

**CAREGIVER  
INFORMATION**



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## Request from People with Alzheimer's

Please...

Be patient with me. My disease is beyond my control.

Accept me the way I am. I still have something to offer you.

Talk with and listen to me. I can't always answer, but I do understand the tone of your voice. Because I cannot remember does not mean that I am dumb.

Be kind to me. Your kindness may be the highlight of my day.

Don't hurry me. Each day I struggle to keep up and understand.

Consider my feelings. I am sensitive to shame, embarrassment, failure, fear and uncertainty.

Don't ignore me.

Treat me with dignity. I am not less of a person because I have Alzheimer's disease.

Remember my past. Remind me of successes, values and worth.

Remember my present. Let me do what I can do. Break down activities into steps I can handle. I respond to encouragement.

Remember my future. I need hope for tomorrow.

Pray for me. Your presence shows true compassion.

# CONTENTS

INTRODUCTION.....	4
STATISTICS ABOUT ALZHEIMER'S DISEASE .....	5
FINDING OUT IF IT'S ALZHEIMER'S DISEASE .....	7
VISITING THE DOCTOR .....	10
SERVICES YOU MAY NEED.....	12
GLOBAL DETERIORATION SCALE FOR DEMENTIA & ALZHEIMER'S DISEASE ....	14
WHEN YOUR LOVED ONE NEEDS MORE HELP.....	15
WHAT IS AN ADULT DAY CENTER?.....	16
PLANNING AHEAD: WHAT DO YOU NEED? .....	18
DECISION MAKING AMONG FAMILY MEMBERS .....	20
YOU CAN MAKE A DIFFERENCE.....	22
THE DO'S AND DON'TS OF WORKING WITH PERSONS WITH DEMENTIA .....	24
CAREGIVER TIPS .....	25
COMPASSIONATE COMMUNICATION WITH THE ALZHEIMER'S PATIENT .....	26
HELPING THE PERSON WITH DEMENTIA TO UNDERSTAND .....	28
PERCEPTION ERRORS IN THE PERSON WHO HAS ALZHEIMER'S DISEASE .....	29
ALZHEIMER'S DISEASE MEDICATIONS – ETHICAL ISSUES .....	30
WHAT CAN I DO WHEN HE/SHE...HIDES THINGS, HOARDS THINGS, STEALS THINGS?.....	33
WHAT TO DO ABOUT HALLUCINATIONS .....	34
WHAT CAN I DO ABOUT PACING?.....	35
WHAT CAN I DO WHEN I LOSE MY PATIENCE? .....	36
HOW CAN I COPE DURING DIFFICULT CAREGIVING? .....	37
MAKING BATH TIME RELAXING .....	39
DRESSING .....	42
HELPING CHILDREN AND TEENS UNDERSTAND ALZHEIMER'S DISEASE .....	43
ALZHEIMER'S DISEASE AND DRIVING.....	46
PLANNING FOR THE HOLIDAYS WHEN ALZHEIMER'S IS PART OF THE FAMILY ..	51
HOME SAFETY FOR PEOPLE WITH ALZHEIMER'S DISEASE .....	54
MEALTIME TIPS.....	57
SLEEP AND ALZHEIMER'S .....	60
SUNDOWNING--WHAT TO DO .....	63
VACATIONING .....	65
VISITING THE PERSON WITH ALZHEIMER'S DISEASE .....	68
REMINISCING .....	70
101 THINGS TO DO .....	72
BOOK LIST FOR THE ALZHEIMER CAREGIVER .....	73

# INTRODUCTION

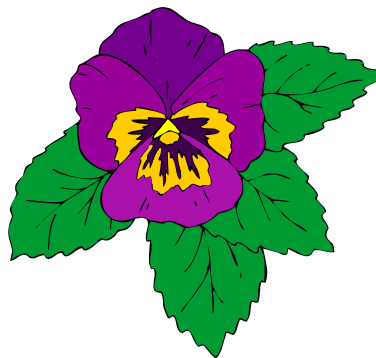
Alzheimer's Disease is a progressive, degenerative disease of the brain. It results in impaired memory, thinking and behavior. An Alzheimer's patient experiences confusion, personality and behavioral changes, impaired judgment and difficulty finding words, finishing thoughts or following directions.

Eventually, the disease leaves the person unable to perform even the simplest tasks of daily living and totally dependent on others for constant care and supervision. One in 10 persons over 65 and nearly half of those over 85 will have Alzheimer's disease. Nearly 80% of these individuals are cared for at home by a family member.

The Alzheimer's Association, Utah Chapter, has put together this informational packet with the goal to help families learn about Alzheimer's disease and related dementias. Since there still is no successful long term treatment for Alzheimer's disease, it is important to learn care techniques that will make coping with this devastating disease just a little easier.

Please use this packet as a reference. We hope that the information offered as well as the resources listed will help give you more confidence in your caregiving.

If you have questions and concerns, please call the Alzheimer's Association office nearest you and talk with a professional staff member or schedule a free care consultation.



## **Our Mission Statement:**

To eliminate Alzheimer's disease through the advancement of research and to enhance care and support for individuals, their families and caregivers.

# STATISTICS ABOUT ALZHEIMER'S DISEASE

The impact of Alzheimer's on individuals, families and our health care system makes the disease one of our nation's greatest medical, social and fiscal challenges.

- An estimated 4.5 million Americans have Alzheimer's disease, according to data based on the number of cases detected in an ethnically diverse population sample and the 2000 U.S. census. In Utah close to 30,000 people have been diagnosed with Alzheimer's disease. Utah has one of the fastest growing elderly population in the country therefore the increase in Utahns with Alzheimer's disease will be dramatic in the years to come if a treatment or cure is not found.
- Those data show that by 2050, the number of Americans with Alzheimer's could range from 11.3 million to 16 million, with a middle estimate of 13.2 million. In Utah the number of people with Alzheimer's disease will rise to almost 100,000 by the middle of the century.
- Finding a treatment that could delay onset by five years could reduce the number of individuals with Alzheimer's disease by nearly 50 percent after 50 years.
- In a Gallup poll commissioned by the Alzheimer Association, 1 in 10 Americans said that they had a family member with Alzheimer's and 1 in 3 knew someone with the disease.
- Increasing age is the greatest risk factor for Alzheimer's. One in 10 individuals over 65 and nearly half of those over 85 are affected. Rare, inherited forms of Alzheimer's disease can strike individuals as early as their 30's and 40's.
- A person with Alzheimer's disease will live an average of eight years and as many as 20 years or more from the onset of symptoms.
- National direct and indirect annual costs of caring for individuals with Alzheimer's disease are at least \$100 billion, according to estimates used by the Alzheimer's Association and National Institute on Aging.
- Alzheimer's disease costs American business \$61 billion a year, according to a report commissioned by the Alzheimer's Association. Of that figure, \$24.6 billion covers Alzheimer health care and \$36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement.
- More than 7 out of 10 people with Alzheimer's disease live at home, where almost 75 percent of their care is provided by family and friends. The remainder is "paid" care costing an average of \$12,500 per year. Families pay almost all of that out of pocket.
- Half of all nursing home residents have Alzheimer's disease or a related disorder. The average cost for nursing home care is \$42,000 per year but can exceed \$70,000 per year in some areas of the country.
- The average lifetime cost of care for an individual with Alzheimer's is \$174,000
- By 2010, Medicare costs for beneficiaries with Alzheimer's are expected to increase 54.5 percent, from \$31.9 billion in 2000 to \$49.3 billion, and Medicaid expenditures on residential dementia care will increase 80 percent, from \$18.2 billion to \$33 billion in 2010, a report commissioned by the Alzheimer's Association concludes.

- The Alzheimer's Association has awarded more than \$150 million in research grants since 1982, according to audited annual financial statements. The federal government estimates spending approximately \$640 million for Alzheimer's disease research in fiscal year 2003.

# FINDING OUT IF IT'S ALZHEIMER'S DISEASE

Memory loss that disrupts everyday life is not part of the normal aging process. It is a symptom of dementia, a gradual and progressive decline in memory, thinking, and reasoning skills. The most common cause of dementia is Alzheimer's disease, a disorder that results in the loss of brain cells.

## TEN WARNING SIGNS:

1. Memory loss that affects job skills. It's normal to forget people's names from time to time, but frequent forgetfulness is cause for concern.
2. Difficulty performing familiar tasks. Anyone can leave a button unbuttoned, but when someone becomes persistently challenged by buttons or other tasks of daily living most people take for granted, that's cause for concern.
3. Language problems. From time to time, anyone can have difficulty finding the right word. But when simple words present problems, or when sentences become incomprehensible, that might signal Alzheimer's disease.
4. Time and place disorientation. It's normal to forget the date or a destination. People with Alzheimer's often feel lost standing across the street from their own homes.
5. Loss of judgment. Anyone can fail to notice that an item of clothing is stained, but when someone dresses completely inappropriate – wearing several shirts or mistaking underwear for a hat – that's cause for concern.
6. Problems with abstract thinking. Anyone can struggle over balancing a checkbook. People with Alzheimer's forget what numbers are for and how to use them.
7. Misplacing things. Anyone can misplace a wallet or keys, but when someone puts a wallet in the refrigerator or keys in the sink, that's cause for concern.
8. Changes in mood or behavior. Changing moods are a fact of life, but people with Alzheimer's disease often exhibit rapid mood changes – from calm to tears to rage – for no apparent reason.
9. Changes in personality. People often become more 'crotchety' as they become elderly, but Alzheimer's disease often makes people paranoid, very confused and/or fearful.
10. Loss of initiative. It's normal to get bored with daily activities, but when people lose much of their get-up-and-go that's cause for concern.

Memory loss and changes in mood and behavior are some signs that you or a family member may have Alzheimer's disease. If you have noticed these signs, it is important to receive a diagnosis. Other health problems can also cause dementia or a decline in intellectual ability severe enough to interfere with a person's daily routine such as:

Stroke  
Head Injury  
Poor nutrition  
Drug reactions  
Metabolic changes  
Depression  
Parkinson's disease  
Huntington's disease  
Pick's Disease  
Lewy Body Disease  
Brain tumors  
Hypothyroidism  
Vitamin B-12 deficiency

Alzheimer's disease is the most common cause of dementia. It is important to identify the actual cause in order for the individual to receive the proper care.

The individual who may have Alzheimer's disease may be able to maximize the quality of his or her life by receiving an early diagnosis. It may also resolve the anxiety of wondering "What is wrong with me?"

An early diagnosis allows more time to plan for the future. Decisions regarding care, living arrangements, financial and legal issues and other important issues can be addressed.

Alzheimer's disease is known to strike persons in their 40s and 50s. This "early onset" form of Alzheimer's disease presents unique planning issues for the individual and family.

There is no one diagnostic test that can detect if a person has Alzheimer's disease. The diagnosis is made by reviewing a detailed history on the person and the results of several tests, including a complete physical and neurological examination, a psychiatric assessment and laboratory tests. Once these tests are completed, a diagnosis of "probable" Alzheimer's disease can be made by process of elimination. However, physicians can be 80 to 90 percent certain their diagnosis is accurate. The process may be handled by a family physician or may involve a diagnostic team of medical professionals, including the primary physician, neurologist (a physician specializing in the nervous system), psychiatrist, psychologist and nurses.

The diagnostic process generally takes more than one day and is usually performed on an outpatient basis. It may involve going to several different locations or even to a specialized Alzheimer diagnostic center.

The diagnostic process involves the following:

1. **Determination of Medical History.** The person being tested and family members will be interviewed both individually and together to gather background information on the person's daily functioning, current mental and physical conditions and family medical history.
2. **Mental Status Evaluation.** The person's sense of time and place, and ability to remember, understand, talk and do simple calculations will be assessed.
3. **Physical Examination.** The physician will evaluate the person's nutritional status and check blood pressure and pulse. The physician will also search for the presence of cardiac, respiratory, liver, kidney and thyroid diseases and atherosclerosis (hardening of the arteries).
4. **Neurological Exam.** This is usually done by a neurologist. The physician will closely evaluate the person's nervous system for problems that may signal brain disorders other than Alzheimer's disease such as strokes, Parkinson's disease, brain tumor or other illnesses that can impair memory and/or thinking.
5. **Laboratory tests.** A variety of laboratory tests will be ordered to help diagnose Alzheimer's disease by ruling out other disorders. An EEG (electroencephalogram) may be ordered to detect abnormal brain wave activity. A CT scan or MRI scan may be ordered to look for evidence of tumors, strokes or blood clots.
6. **Psychiatric, psychological and other evaluations.** A psychiatric evaluation can rule out the presence of other illnesses, such as depression, which can result in memory loss similar to dementia of the Alzheimer type. Neuropsychological testing may also be done to test memory, reasoning, writing, vision-motor coordination and ability to express ideas.

Once testing is completed, the diagnosing physician or other members of the diagnostic team will review the results of the examinations, laboratory tests and other consultations to arrive at a diagnosis. IF all tests results appear to be consistent with Alzheimer's disease, the clinical diagnosis will be "probable Alzheimer's disease" or "dementia of the Alzheimer's type." If the symptoms are not typical, but no other cause is found, the diagnosis will be "possible Alzheimer's disease."

Although researchers have made enormous progress in diagnostic testing, the only way to prove Alzheimer's disease is through an autopsy.

**GETTING AS ACCURATE A DIAGNOSIS AS POSSIBLE IS TOP PRIORITY**

Find a physician experienced in diagnosing and treating dementia.

If need be, get a second opinion.

# VISITING THE DOCTOR

## **GETTING A DIAGNOSIS.**

Sometimes it is very difficult to get the person with memory loss to go to the doctor for a diagnosis or even just a routine check up. Try to restate your position by validating their fears. Agree with their arguments, but also state your position, *“I know you are healthy and you feel you don’t need to see a doctor, but I would feel so much better knowing that you have a clean bill of health.”* In many cases, the person is familiar with the symptoms of Alzheimer’s, and fears getting an actual diagnosis. You may try to reassure the person with memory loss that there are some treatable conditions that cause similar symptoms (new medications, hearing loss, lack of sleep, etc.) Try not to take their disagreements personally. The following suggestions may help.

**Have the caregiver go as a patient, also.** Tell the person with memory loss you need to go to the doctor. Ask if he or she will come along. The caregiver could get their blood pressure checked, etc. by a nurse. This may make the person feel more at ease about going. At the same time, the physician may evaluate the person with memory loss.

**Ask the physician to call the person with memory loss to schedule an appointment.** Often, the doctor’s office will work with the caregiver on getting the person with memory loss evaluated. The office could call and tell them to schedule an appointment since they haven’t been in for some time. Most often, the person will schedule with the doctor’s encouragement. You may want to make sure that the physician you select is experienced in diagnosing and treating dementia. Call our office for a referral listing of physicians.

**Get the doctor or pharmacist involved.** The person with memory loss may be told that an evaluation or trip to the doctor may be required to continue a current prescription. This should persuade them to schedule the appointment they need.

**Call ahead and explain your concerns.** Many individuals in the early stages of Alzheimer’s behave well in short social situations, making it difficult for a doctor to pick up on problems without some warning from the caregiver. Call ahead and give a description of their behavior or bring with you, or mail ahead, a log of behaviors you have been noting which includes dates and details of incidences which indicate a change in personality or cognition.

**As a last resort...** If you are still struggling to get the person with memory loss to the doctor, give yourself permission to alter the truth. We were told of a caregiver that wrote the person with memory loss a letter resembling that of the insurance company, stating that the person was due for a physical. These are called “therapeutic fibs” and are done with the health and well being of the person with memory loss in mind...they must see a physician. The sooner a diagnosis can be made, the sooner other possible causes can be diagnosed or ruled out and appropriate treatment started. Also, legal and financial planning can begin in order to prepare for the future.

## **IN THE LATER STAGES.**

In the later stages of Alzheimer’s disease you may experience different obstacles when trying to get the person with the disease to see his or her physician. Obstinate behavior and acting out may make your trip difficult. Sometimes just getting the person out the

front door may be a problem. The following suggestions may help your trip to the doctor go smoothly.

**Simplify what you tell the impaired person.** Get them ready to go. If they question where they are being taken, you can tell them “to the doctor and then out to lunch or out for ice cream.” This may take the emphasis off of the doctor visit. Also, try to be very reassuring- this may be a frightening and strange experience for them.

**Take someone with you.** If possible, take a third person along to help in the car while you drive as well as to assist you in occupying the person while you wait. If you don't have a third person, make sure that you have a child safety lock on the door where the person is sitting.

**Plan the trip out well.** Know where you are going. You may also call ahead and warn the nurse and/or doctor in advance about the person's behavior if you will be waiting for a long period. Bring distractions along such as snacks or pictures to look at.

**Use other physical problems as an excuse.** If the person has any discomforts such as a hip hurting, explain that the doctor will give them something to help their hip.

**A prescription may help calm.** If the person is extremely anxious and acting out, a prescription to relax them may make the trip easier for both of you.

**See if the doctor will do a home visit.** It may be rare today, but there are still some visiting physicians. If not the doctor, a nurse practitioner or visiting nurse service may be able to do an assessment and report to the physician- as long as the problems are not emergencies.

## SERVICES YOU MAY NEED

*There are many types of services available to assist you throughout the course of Alzheimer's disease. Although you may not need all these services immediately after receiving a diagnosis, it's important to identify what's available in your community. **Call the Alzheimer's Association office (801) 265-1944 or our 365/24/7 toll free number at 1-800-272-3900.***

**Medical Services:** Families report they are most satisfied with a specialist who is well informed about Alzheimer's disease. This may be a neurologist, geriatrician, psychiatrist or a family doctor who is experienced in treating people with the disease.

**Legal Services:** Legal planning should begin soon after a diagnosis has been made. Planning should involve putting together documents that authorize another person to make health care and financial decisions, including plans for possible long-term care coverage.

An attorney can explain issues related to durable power of attorney for health care and finances, living wills and trusts, future medical care, housing and other key considerations. There are elder law attorneys who specialize in issues affecting older adults.

If the person with Alzheimer's has the legal capacity – the level of mental functioning necessary to sign official documents – he or she should actively participate in legal planning.

**Financial Services:** Important financial decisions will have to be made throughout the course of the disease. Attorneys, accountants and financial planners can help. If possible, include the person with Alzheimer's in the discussions.

Financial assistance and health care benefits may be obtained through several government sources. There are two types of entitlement programs that persons with Alzheimer's may apply for: those that provide income and those that help pay for medical expenses. Some of these include Social Security Disability, Supplemental Security Income, General public Assistance, Medicare and Medicaid. Contact your elder attorney, financial advisor or the agency directly or call the Alzheimer Association.

**Helpline:** The Alzheimer's Association Helpline is staffed by trained volunteers and professionals experienced in issues related to the disease. Helpline specialists are available to offer ongoing support suggest tips for care giving and provide specific information on resources that may help you. **The helpline is available 365/24/7 and the number is (800) 272-3900.**

**Support Groups:** Support groups are available for caregivers and family members throughout the disease process. Support groups are located throughout the state of Utah and are held at various times of day to accommodate the caregiver. Support groups for persons with Alzheimer's disease are also being formed. You can talk with others who are experiencing similar situations in a safe, non-judgmental group setting.

**Information:** You can find information on everything from diagnosis and treatment to care giving and support groups through the Alzheimer's Association and also on the web sites for the Utah chapter [www.alz.org/utah](http://www.alz.org/utah) or the National Alzheimer Association web site [www.alz.org](http://www.alz.org)

**Respite Care:** refers to a short time of rest or relief. It allows caregivers a break from day-to-day duties and provides the person with Alzheimer's opportunities to interact with others. Three types of respite care available are:

- **Day Services:** Programs in adult day centers can give the person with Alzheimer's an opportunity to socialize with others, exercise and engage in simple activities.
- **Home Care:** Visiting nurses, home health aides, homemakers and volunteers can provide services at home such as bathing, dressing or companionship while you go out for a while.
- **Residential Respite:** Some hospitals, nursing homes and other residential facilities offer short-term stays of a few days or a few weeks.

**Residential Care:** The type of residential care you may need will probably vary depending on the stage of the disease. Housing services are generally grouped in two categories:

- **Assisted Living:** Also known as board and care homes, assisted living is a term for residential care settings that combine housing, personalized supportive services and health care. These settings offer more services than independent living but fewer than a skilled nursing facility.
- **Skilled Nursing:** Also known as nursing home care, this type of care provides an intermediate or skilled nursing setting for those who require more services. Some are designed to provide specialized care for persons with dementia.

**Hospice Services:** Designed to help people near the end of life, hospice programs combine at-home and skilled nursing services. Today, more hospices are offering specialized programs for persons with Alzheimer's disease.

**Other Support Services:** Other support services may be available from your local Department of Aging, Department of Health, senior citizens' agency, religious-affiliated service agencies and patient education departments of hospitals. Also, private physicians, social workers, nurses, psychologists and counselors may provide such services.

# GLOBAL DETERIORATION SCALE FOR DEMENTIA & ALZHEIMER'S DISEASE

Stages are general guides and symptoms vary greatly. Every person is unique. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to other people, but survival can range from three to 20 years, depending on age and other health conditions.

GDS STAGE	CLINICAL PHASE	CLINICAL CHARACTERISTICS
1. No Cognitive Decline	Normal	The person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms.
2. Very Mild Cognitive Decline	Forgetfulness	May be normal age-related changes or earliest signs of Alzheimer's disease. The person may feel that he/she is having memory lapses--forgetting familiar words or the location of everyday objects. But no symptoms can be detected during a medical exam or by friends, family or co-workers.
3. Mild Cognitive Decline	Early Confusional	May have gotten lost traveling to unfamiliar location, co-workers aware of poor performance, word and name finding deficit evident, little retention of recently read material, decreased ability to remember names after introduction, lost objects of value, concentration deficit, trouble with planning and organizing. Denial begins, mild to moderate anxiety.
4. Moderate Cognitive Decline	Mild or early-stage Alzheimer's disease	Forgetfulness of recent events, deficit of personal history, decreased ability to travel, handle finances, and perform complex tasks. Clear-cut deficits, concentration deficits. Remains oriented to time and person. Recognizes familiar persons and faces. Denial becomes prominent defense, withdrawal from challenging situations, moodiness.
5. Moderately Severe Decline	Moderate or mid-stage Alzheimer's disease.	Person can no longer survive without assistance, unable to recall address or phone number, names of close family members such as grandchildren but may remember names of spouse and own children, disoriented to time, place. Requires no assistance eating or toileting, but may dress inappropriately, i.e. shoe on wrong foot therefore needs assistance dressing.
6. Severe Cognitive Decline	Moderately severe or mid-stage Alzheimer's disease	May forget name of spouse, unaware of recent events and experiences in their life, retain some sketchy knowledge of their past life, unaware of surroundings, year, season, difficulty counting, will require assistance with activities of daily living. Sleep patterns frequently disturbed. Personality and emotional changes occur; may talk to imaginary people, talks to own reflection in mirror, repetitive behaviors, anxiety, agitation, paranoia, delusional, obsessive, occasionally violent behavior. Loss of initiative, loss of willpower and apathy. May wander or become lost.
7. Very Severe Cognitive Decline	Severe or late-stage Alzheimer's disease	Lose ability to respond to environment, unable to carry on a conversation, may still say words or phrases. Incontinence; needs assistance in toileting and personal care. Needs help eating. May be able to walk but is at risk of falling. Focal neurological signs and symptoms common. Reflexes abnormal, muscles grow rigid, swallowing is impaired. May lose ability to smile or sit without support.

# WHEN YOUR LOVED ONE NEEDS MORE HELP...

**If the Caregiver** wants to keep the patient at home, needs a break or respite time to alleviate stress, needs time to get chores done and is becoming isolated due to caregiving responsibilities and if....

**The patient** would benefit from social interaction with peers, would benefit from an activity program that provides physical and mental stimulation...

Then an **Adult Day Care** can provide a secure, professionally supervised social activity program including exercise, outdoor activities, music, arts and crafts. Financial assistance may be available. Adult day health care also provides physical, speech and occupational therapy and can be covered by Medicaid. Caregiver support services, information and referral and Safe Return registration may be available.

**If the Caregiver** is frail or elderly or is risking health, family or career to care for a loved one and if...

**The patient** is at risk of wandering and does not present challenging behaviors, does not require care for chronic medical conditions, has early to mid-stage dementia and can partially assist with activities of daily living...

Then **Dementia Care Assisted Living** may be the choice. Most dementia care communities are secured and provide medication supervision, a recreational program and assistance with activities of daily living in a residential setting. Assisted living communities do not accept residents with chronic medical conditions and cannot accept Medicare/Medicaid reimbursement. Some do not accept non-ambulatory or incontinent residents. Some offer Hospice services for end-of-life care.

**If the patient** has all of the above or has early- to terminal-stage dementia, is ambulatory or non-ambulatory, is continent or incontinent, has challenging behaviors or needs a locked environment, has diabetes or other chronic health issues, or needs full assistance with activities of daily living and/or needs Hospice care....

Then **Dementia Care with Licensed Nursing** would need to be considered. A few dementia care communities provide 24-hour licensed nursing services in a secured or locked environment. They combine a residential care setting with the staffing of a skilled nursing facility. These communities accept residents with diabetes and other chronic disease, as well as late-stage and Hospice patients. Medicare/Medicaid does not reimburse care costs in these communities.

If the patient does not wander, has or needs a feeding tube, has or needs a permanent IV, has stage 3 or 4 wounds, has a serious infection or needs Medicaid reimbursement option, then...

A Skilled Nursing Facility is needed. Skilled nursing provides custodial care, intensive medical care and 24 hour supervision in a medical setting. While most skilled nursing facilities are not locked, a few provide a secure environment and specialized care for the memory impaired. Not all skilled nursing facilities accept Medicaid patients. Funding options differ among facilities and should be verified before placement.

# WHAT IS AN ADULT DAY CENTER?

Adult day services are community-based group programs designed to meet the needs of functionally and/or cognitively impaired adults through an individual plan of care. These licensed, structured, comprehensive programs provide a variety of health, social, recreational and other related support services in a protective setting during any part of a day.

Who benefits from Adult Day Services?

Older adults who are physically impaired, are mentally confused, require supervision, need increased social opportunities, require assistance with personal care, are limited in ability to function independently in the community, but do not require 24 hour care are the ones who benefit from adult day services.

What are the goals of Adult Day Services?

- Strengthen and maintain a client's maximum level of independence within their home and community.
- Assist in the monitoring of health status and to make appropriate referrals within the community.
- Provide support, respite and education for family caregivers.
- Provide peace of mind for family caregivers who are employed during the day.
- Provide an active, structured program that meets the needs of each individual client.
- Foster socialization and peer interaction.
- Maintain client's present level of functioning, preventing or delaying changes.

How does an Adult Day Center benefit the caregivers?

Allows caregivers the ability to continue their careers, or have time to run errand or engage in social activities, while knowing that their family member is benefiting from the following services:

- A supervised environment with licensed staff.
- Spending a satisfying day engaged in activity with peers.
- Attention to health, social and emotional needs.

Adult day care provides education, counseling and support to the caregiver.

## What services does an Adult Day Center offer?

- Qualified, well trained staff
- Safe, supervised environment
- Transportation
- Socialization
- Meals and snacks
- Mental stimulation
- Sensory stimulation
- Music, movement, art & pet therapy
- Intergenerational activities
- Community outings
- Personal care
- Health screening & monitoring
- Counseling
- Educational programming
- Varied therapeutic recreational group and individual activities

*Information provided by UADSA (Utah Adult Day Services Association)*

# PLANNING AHEAD: WHAT DO YOU NEED?

Everyone, especially individuals diagnosed with Alzheimer's disease, should plan for the future. Legal planning should begin soon after a diagnosis is made and includes putting in place documents that:

- Authorize another person to make health care and financial decision.
- Include financial plans for long-term care coverage.

If the person with Alzheimer's has legal capacity—the level of mental functioning necessary to sign official documents—he/she should actively participate in the legal planning process. An attorney can help determine the level of legal capacity required to execute a particular document since the level of legal capacity required may vary from one document to another.

- Talk with the person.
  - Find out if the person with Alzheimer's understands what is being explained and asked of them.
- Ask for medical advice, if needed.
  - Consult a medical professional if there is a question as to whether or not the person with Alzheimer's has legal capacity.
- Take inventory of existing legal documents.
  - Check to see if living wills, trusts and powers of attorney were executed prior to the diagnosis of Alzheimer's disease.

A caregiver of an individual who no longer has legal capacity to execute powers of attorney or trusts may have to become that individual's guardian or conservator. A guardian has the legal authority to make decisions regarding the care and custody of the person with Alzheimer's. The guardian who manages assets is known as the conservator.

It is important to obtain legal advice and services from an attorney who practices in the area of elder law. Call the Alzheimer Association for referrals. Free legal advice may be available from Legal Services at 328-8891.

**Prepare for your legal appointment**—bring all documents relating to the assets of the individual with Alzheimer's disease. These documents include:

- An itemized list of assets with current value, including whose names are on the accounts or ownership documents.
- Copies of all estate planning documents, including wills, trusts and powers of attorney
- Copies of all deeds to real estate
- Copies of recent income tax returns
- Life insurance policies and cash values of policies
- Health insurance policies or benefit booklet
- Admission agreements to any health care facilities
- A list of names addresses and phone numbers of involved family members, financial planners, accountants and caregivers.

**Talking with your attorney:** Important issues include:

- Options for health care decision-making and property management for the person with Alzheimer's
- Possible coverage of long-term care services including what's provided by Medicare and other health insurance.

**Tips for legal planning:**

- Always name a successor or "back up" agent in the event that the primary agent becomes unable to or unwilling to act.
- Consider a neutral third person as an agent under the power of attorney if immediate family members don't get along.
- If there is no family member available who has the time or expertise to manage the estate of the person with Alzheimer's disease, consider having a bank manage the estate.
- Be sure that all designated individuals have a copy of the power of attorney and have access to the original document.
- Be sure physicians and other health care providers have a copy of the power of attorney for health care and assigned living will on file.
- Inquire whether or not the health care agent has authority to consent to brain autopsy.

*Understand your goals and values:*

- Where do you want to live?
- How do you want to live?
- How will you support yourself?
- How will you support those who depend on you?
- How will you pay for long-term care, if necessary?

*Make plans:*

- Carefully review your assets.
- Make sure you understand how you own what you own.
- Seek advice from professionals: financial planners, accountants, lawyers, geriatric care managers, health care providers.
- Arrange your assets and finances to suit your goals and values.
- Make arrangements to receive appropriate health care and assistance for daily living.

*Use appropriate legal tools to achieve your goals and values:*

- Advance health care directives: Special Power of Attorney for Health Care; POLST; living will.
- General Durable Power of Attorney for Finances
- Will
- Other appropriate tools (for example: trust, guardianship, conservatorship, representative payee, joint ownership arrangements, and contractual beneficiary arrangements.)

Review the Legal Documents you have executed every few years or when significant changes have occurred.

# DECISION MAKING AMONG FAMILY MEMBERS

## *A MEETING OF THE MINDS IS NEVER EASY*

Making decisions about the care of a loved one with dementia is hard under any circumstances. Doing this with family members can add additional elements of difficulty. Here are some sources of possible conflict among family members:

- Different ways of understanding and coming to terms with the illness
- Different grief reactions to the losses involved in the illness.
- Different histories and relationships with the person with dementia.
- Different histories and relationships with each other as family member.
- Unequal sharing of the care giving responsibilities by family members.
- Limited resources of time, energy, support and/or finances for care giving
- Surfacing of old family conflicts through decision-making process
- Existing disharmony between family members.
- Limited experience as a family with joint decision-making

Does this mean that you shouldn't make decisions together? No, it definitely is preferable to work with each other in tackling the hard job of caregiving. However, it is important to recognize from the beginning the possible problems involved and to gear your planning around this awareness. Here are some things which can make planning together a smoother process:

- 1) Start to communicate with each other as soon as the diagnosis is known.
- 2) Commit to learning about the illness and the community resources available to help.
- 3) If at all possible, schedule a family meeting with all members present –preferably in person.
- 4) Set an agenda for the meeting and keep it focus on caregiving issues: *it is not the time or place to rehash or resolve old family conflicts.*
- 5) Focus the meeting on issues like:
  - a) *Share information about the disease itself:* it is important to be as knowledgeable as possible about what this disease means.
  - b) *Discussing the current situation of person with disease,* their abilities and limitations, their level of activity during the day, their sleeping pattern, current living situation, personal safety and their emotional and social needs.
  - c) *Assessing the current resources available in the family* – emotional and otherwise; be realistic about what can be done and who can do it.
  - d) *Assessing the resources available in the community:* families do not have to do everything themselves. In fact, most families utilize help from outside sources throughout the course of the disease.
  - e) *Developing a plan of action that everyone can agree upon:* Be specific about things that need to be done, who will do them and when. Focus on immediate, intermediate and long-term actions.
  - f) *Deciding on a time and way to flow up on the action plans:* If possible, set a date for a follow-up meeting to check progress.
  - g) *Making a written summary of the meeting* – communicated by letter or email. Everyone needs to know what was agreed upon.



# YOU CAN MAKE A DIFFERENCE

## TEN WAYS TO HELP AN ALZHEIMER FAMILY

Alzheimer's causes significant changes in family life. Spouses and children – often including school age youngsters – become caregivers. Caregiving can make recreation, chores and even employment difficult or impossible to maintain. The uninsured cost of care can wipe out savings, too. It's no wonder that 80 percent of Alzheimer caregivers report high levels of stress and stress-related illness.

One in ten American families has a loved one with Alzheimer disease; and one in three adults know someone with the disease. Changes are you do too. You may want to offer your help, but worry that you'll say or do the wrong thing. You should know that:

Alzheimer caregivers

- *feel alone and disconnected from friends*
- *need assistance, but are reluctant to ask*
- *are often unable to do errands or complete household tasks*
- *experience stress, sometimes severe*
- *need a break from caregiving, but may not have anyone to relieve them or refuse assistance when it's offered.*
- *Are looking for someone to listen*

And those with Alzheimer's

- *face an uncertain future*
- *must adjust to new schedules and changing roles and responsibilities*
- *worry about overwhelming family caregivers*
- *strive to maintain an active and independent lifestyle*
- *may look the same, but act differently*

A friend is an important source of support for the Alzheimer family. Even if they live far away, there's still plenty you can do. Here are ten easy ways to help:

### **1. Keep in touch**

Maintain contact with family members. A card, a call, or visit all mean a great deal. Family members, including the person with Alzheimer's, will benefit from your visits or calls. Continue to send cards, even if you don't get a response. It's a simple, yet important way to show you care.

### **2. Do little things – they mean a lot**

When cooking, make extra portions and drop off a meal (a freezable and disposable container). If you're on your way out to do an errand, check with a family member to see if there's anything they need. Surprise the caregiver with a special treat, such as a rented movie, an audiobook of last week's church service or a gift certificate for a massage or a dinner out.

### **3. Give them a break**

Everyone needs a little time for themselves. Offer to stay with the Alzheimer person so family members can run errands, attend a support group meeting or take a short trip. Even if the caregiver does not leave the house, this will provide some personal time. Chances are the person with Alzheimer's will also enjoy the break.

#### **4. Be specific when offering assistance**

Caregivers find it hard to ask for something specific. Prepare a "to do list" of hard-to-get-to projects (e.g. laundry, dusting, yard work, medical bills). Figure out what you can do, and then dedicate some time -- on a weekly or monthly basis -- to helping the family tackle some of these tasks.

#### **5. Be alert**

Learn about Alzheimer's and how it impacts the family. Most people with Alzheimer's "wander" at some point and could become lost in their own neighborhoods. Know how to recognize a problem and respond. Take time to learn about other common behaviors and helpful care techniques.

#### **6. Provide a change of scenery**

Plan an activity that gets the whole family out of the house. Make a reservation at a restaurant and ask for a table with some privacy. Or, invite the family to your house or to a nearby park for a picnic.

#### **7. Learn to Listen**

Sometimes, those affected by Alzheimer's just need to talk with someone. Ask family members how they're doing and encourage them to share. Be available when the caregiver is free to talk without interruptions. Be a compassionate listener, try not to question or judge, but rather, support and accept.

#### **8. Care for the caregiver**

Encourage caregivers to take care of themselves. Pass along useful information and offer to attend a support group meeting with them. The Alzheimer's Association has information available and sponsor telephone "Helplines" and support groups.

#### **9. Remember all family members**

The person with Alzheimer's will appreciate your visits, even if unable to show it. Talk with the person the way you'd want to be talked to. Spouses, adult children and even young grandchildren are all affected in different ways by a relative's Alzheimer's disease. Be attentive to their needs too.

#### **10. Get involved**

Unless a prevention is found, 14 million Americans will have Alzheimer's disease by 2050. There are many things you can do to help families today and prevent further devastation tomorrow. Make contribution to the Alzheimer Association or volunteer at your local chapter. Join the Association's annual Memory Walk to raise awareness and funds for chapter programs and services. Ask your legislator to support funding of research and programs to help Alzheimer families.

# THE DO'S AND DON'TS OF WORKING WITH PERSONS WITH DEMENTIA

## DO:

**Treat the person as an adult.** Although the person with dementia is confused, her or she is an adult and deserves to be treated like one.

**Be sensitive to the environment.** Is it calm? Quiet? Is the temperature comfortable? Is the lighting too bright? An uncomfortable environment may be the cause of catastrophic reactions.

**Help the person to remain as independent as possible.** It may be quicker to do things for him/her, but it is better for the person to do things for himself/herself.

**Simplify instructions.** Give one direction at a time to avoid confusion.

**Establish a familiar routine.** Activities within the routine should be varied as appropriate.

**Speak to the person as if he or she understands.** Give the individual the benefit of the doubt. He or she may surprise you.

**Respond** to the person's feelings, not just the words expressed.

**Be flexible.** Creativity helps when working with a person with dementia.

**Learn as much about the person's past as you can.** This will help you immensely in planning programs and when calming a person who is upset.

**Provide encouragement.** Imagine not knowing who or where you are. You'd need encouragement, too.

**Be patient.** Give the person extra time to respond to questions or requests. Do not bombard the person with multiple questions or requests. Rushing the person usually winds up frustrating both of you.

## Don't:

**Speak to the person as if he or she were a child.** This can cause angry reactions and it indicates a lack of respect.

**Scold the person.** He or she is not intentionally making a mistake. Instead, quietly and gently point out the behavior and suggest alternatives.

**Speak to the person in negatives.** You'll get a better response if you say, "come with me" than you will with, "You can't go there." Avoid negative phrases like, "don't do that" or "You're doing it the wrong way."

**Startle the person.** Approach the person from the front. Be sure he or she sees you before you begin to speak.

**Assume that every person with dementia is the same.** Dementia affects people and progresses differently in different people.

**Be afraid to touch the person or give a hug once in a while.** Express some affection. The person with dementia likely does not get enough of it.

**Talk "around" a person with dementia, as if he or she isn't there.** He or she may understand more than you think.

**Give up!** Never, never give up on someone!

# CAREGIVER TIPS

## 1. Re-direct:

**Example:** Petite Mrs. D's six foot husband was angrily telling her to leave because she wasn't his real wife. She replied that she would leave, but first they needed to fix sandwiches and have chocolate cake, which he loved.

**Result:** By the time they finished eating his favorite food, he had forgotten she wasn't his real wife and he had told her to leave.

## 2. Therapeutic Fib:

**Example:** Mrs. S is in a care facility while her caregiver daughter is receiving chemotherapy for her own illness. When Mrs. S tells her she is going to go home NOW, her daughter tells her, "Good idea! We can't today but let's plan for Tuesday."

**Result:** Mrs. S is calmed and reassured. Her daughter is not stressed. Who knows when or if Tuesday will be remembered!

## 3. Never Argue:

**You can never, never, win!** It only frustrates you both. Whatever a person with Alzheimer disease says is REAL for them...YOU CAN'T USE LOGIC WITH ANYONE WHO HAS LOST THEIR REASONING ABILITY.

**Example:** Mrs. B woke her caregiver daughter in the middle of the night, terribly distraught; claiming someone named Jan had stolen the crock pot from the kitchen. Her daughter, half asleep, agreed she thought Jan stole it too and she would make her bring it back first thing in the morning. Mrs. B went back to bed and her daughter drifted back to sleep wondering who Jan was and knowing they didn't have a crock pot.

**Result:** No fight, no argument, just back to sleep.

**Learning these three basic rules may be the most effective, valuable thing you do. Practice them until they come easily for you!**

# COMPASSIONATE COMMUNICATION WITH THE ALZHEIMER'S PATIENT

(By Liz Ayres: Volunteer and former caregiver)

## Don't:

Don't Reason  
Don't Argue.  
Don't Confront.

Don't remind them they forget.  
Don't question recent memory.  
Don't take it personally.



*Oops! You must be kidding  
You mean I can't reason???  
Or argue??? Or remind...???*

## DO:

Give short, one sentence explanations.  
Repeat instructions or sentences *exactly* the same way.  
Allow plenty of time for comprehension.  
Eliminate "but" from your vocabulary; substitute "nevertheless".

Agree with them or distract them to a different subject or activity. *Hmmm...accept*  
Accept the blame when something's wrong (even if its fantasy). *the blame?*  
Leave the room, if necessary, to avoid confrontations. *This is gonna be tough!*

Respond to the feelings rather than the words.  
Be patient and cheerful and reassuring. Do go with the flow.  
My appeal to you: Please elevate your level of generosity and graciousness.



## Remember:

They are not crazy or lazy. They are saying normal things and doing normal things, *for an Alzheimer's disease patient*. If they were doing things, or saying things, to deliberately aggravate you, they would have a different diagnosis. Some days they'll seem normal, but they are *not*. Their reality is now different than yours and *you cannot change them*. You can't control the disease; you can only control your reaction to it.

Their disability is memory loss. They cannot remember and can't remember that they cannot remember. They'll ask the same question over and over *believing it's the first time they've asked*.

They do not hide things; they *protect* things by putting them in a safe place and then forgetting they've done so. Do not take 'stealing' accusations personally.

They are scared all the time. Each patient reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive, or physically combative. They may even do them all at different times, or alternate between them. Anxiety may compel them to *shadow you* (follow you everywhere). They can't remember your reassurances. Keep saying them.

**Once dementia is diagnosed, the patient is excused 100% of the time.**

**Examples:**

<p style="text-align: center;"><b><u>Don't Reason</u></b></p> <p><b>Patient:</b> "What doctor's appointment? There's nothing wrong with me."</p> <p><b>Don't:</b> (reason) "You've been seeing the doctor every three months for the last two years. It's written on the calendar and I told you yesterday and this morning."</p> <p><b>DO:</b> (short explanation) "It's just a regular check-up." (accept blame) "I'm sorry if I forgot to tell you."</p>	<p style="text-align: center;"><b><u>Don't ask questions of recent memory</u></b></p> <p><b>Patient:</b> "Hello, Susie. I see you've brought a friend with you."</p> <p><b>Don't:</b> (question memory) "Hi, Mom. You remember Eric don't you?....What did you do today?"</p> <p><b>DO:</b> (short explanation) "Hi, Mom. You look wonderful! This is Eric. We work together."</p>
<p style="text-align: center;"><b><u>Don't Argue</u></b></p> <p><b>Patient:</b> "I didn't write this check for \$500. Someone at the bank is forging my signature."</p> <p><b>Don't:</b> (argue) "What?" Don't be silly! The bank wouldn't be forging your signature."</p> <p><b>DO:</b> (respond to feelings) "That's a scary thought." (reassure) "I'll make sure they don't do that." (distract) "Would you help me fold the towels?"</p>	<p style="text-align: center;"><b><u>Don't take it personally!</u></b></p> <p><b>Patient:</b> "Who are you? Where's my husband?"</p> <p><b>Don't:</b> (take it personally) "What do you mean— who's your husband? I am."</p> <p><b>DO:</b> (go with the flow, reassure) "He'll be here for dinner." (distract) "How about some milk and cookies? Would you like chocolate chip or oatmeal?"</p>
<p style="text-align: center;"><b><u>Don't Confront</u></b></p> <p><b>Patient:</b> "Nobody's going to make decisions for me. You can go now...and don't come back!"</p> <p><b>Don't:</b> (confront) "I'm not going anywhere and you can't remember enough to make your own decisions."</p> <p><b>DO:</b> (accept blame or respond to feelings) "I'm sorry this is a tough time." (reassure) "I love you and we're going to get through this together." (distract) "You know what? Don has a new job. He's really excited about it."</p>	<p style="text-align: center;"><b><u>Do repeat exactly</u></b></p> <p><b>Patient:</b> "I'm going to the store for a newspaper."</p> <p><b>Don't:</b> (repeat differently) "Please put your shoes on." "You'll need to put your shoes on."</p> <p><b>DO:</b> (repeat exactly) "Please put your shoes on." "Please put your shoes on."</p>
<p style="text-align: center;"><b><u>Don't remind them they forget</u></b></p> <p><b>Patient:</b> "Joe hasn't called for a long time. I hope he's okay."</p> <p><b>Don't:</b> (remind) "Joe called yesterday and you talked to him for 15 minutes."</p> <p><b>DO:</b> (reassure) "You really like talking to Joe, don't you?" (distract) "Let's call him when we get back from our walk."</p>	<p style="text-align: center;"><b><u>Do eliminate 'but', substitute 'nevertheless'</u></b></p> <p><b>Patient:</b> "I'm not eating this. I hate chicken"</p> <p><b>Don't</b> (say 'but') "I know chicken's not your favorite food, but it's what we're having for dinner."</p> <p><b>DO:</b> (say 'nevertheless') "I know chicken's not your favorite food, (smile) <i>nevertheless</i> I'd appreciate it if you'd eat a little bit."</p>

# HELPING THE PERSON WITH DEMENTIA TO UNDERSTAND

## **Your approach to communicating:**

Communication can become increasingly challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person with Alzheimer's disease may appear. Although the person may not always respond, they still require and will benefit from continued communication.

**Words must be chosen carefully.** To enhance your interactions try some of the following techniques:

**Identify yourself.** Approach from the front and tell (or remind) the person who you are.

**Address the person by name.** This not only courteous, but also helps orient the person and gets their attention.

**Use short, simple, familiar words and sentences.** Don't overwhelm the person with lengthy requests or stories. Speak concisely and keep to the point. In some cases, slang words or words familiar within the person's culture, may be helpful.

**Talk slowly and clearly and be knowledgeable about hearing problems.** Be aware of speed and clarity when speaking, keep voice at a moderate level and do not raise your voice to a higher sounding pitch.

**Give only one step directions.** Break tasks and instructions into clear simple steps, giving one step at a time.

**Ask only one question at a time.** Don't overwhelm or confuse the patient with too many questions at a time.

**Patiently wait for a response.** The person may need some extra time to process your request. Give a little time and encouragement to respond.

**Repeat information or questions.** If the person does not respond, wait a moment and ask again. Use the same phrase and words as before.

**Turn questions into answers.** Try providing the solution, rather than the question. For example say "The bathroom is right here" instead of asking "Do you need to use the bathroom?"

**Avoid pronouns (he, she, it).** Instead of saying "Here IT is," try "here is your HAT."

**Make negatives more positive.** Instead of saying "Don't go there" try saying "Let's go here."

**Try again later.** If the patient looks like he's not paying attention, try to communicate again a little later.

**Treat the person with Alzheimer's disease with respect.**

**Never talk down and always remain patient.**

# PERCEPTION ERRORS IN THE PERSON WHO HAS ALZHEIMER'S DISEASE

Perception errors are the result of the loss of brain cells that handle vision.

A person with this disease may:

Walk into walls.

Refuse to walk on dark or light floors (they see them as holes)

See the change of floor pattern as a step down or up

Think the TV program they are watching is real.

Not realize the car is moving and open the door.

Become terrified at their own image in a mirror  
(cover or remove the mirrors when that time comes)

Think radio voices are strangers in the house

See windows as doorways

See electric cords as crawling snakes

Become confused by shadows or glare

**Be prepared for errors in perception.**

**Be supportive**

**Give simple explanations**

**Try to redirect their attention toward something familiar or something they like.**

# ALZHEIMER'S DISEASE MEDICATIONS – ETHICAL ISSUES

There are currently several pharmaceutical treatments prescribed for people with Alzheimer's disease that may improve cognitive functions such as memory and reasoning. There are also medications available that may modify behaviors such as aggression and agitation. Research is moving quickly on chemical compounds which can slow the progression of the disease or even reverse some of the effects of the disease. In light of this fast moving research it is important to keep the following treatment goals in mind as new medications become available:

- What issues should patients and families consider when making decisions about the use of prescription medications to treat Alzheimer's disease?
- If a particular treatment for Alzheimer's exists, are families ethically obligated to make sure the patient receives that treatment?

In 1997, the Alzheimer's Association Ethics Advisory Panel made several conclusions regarding research on new therapies. The panel concluded that it is important for consumers to consider the goals of various therapies, especially as new treatments are being developed. Patients and families should consider whether the medication is proving effective, whether it is improving quality of life for the person with Alzheimer's, whether it is making the task of providing care easier or more difficult, and whether it should be applied in all stages of Alzheimer's. The panel suggested that physicians should pay attention to questions posed by the family in relation to therapeutic goals and consider the withdrawal of treatments based on perceptions by family members that burdens outweigh benefits.

Below are several questions that professionals, family members and people with Alzheimer's may want to consider in the highly personal decisions about therapeutic goals:

## ***With regard to cognitive enhancement:***

1. To what extent has the diagnosed person and their family placed hope in medications and are these hopes realistic?
2. What is the perception of the diagnosed person and their family regarding the effects—positive and negative—of these medications?
3. If the medication slightly improves cognition but lowers quality of life or complicates caregiving, is it worth using?
4. What are the patient's or family's therapeutic goals and how long do they wish to use the medication?

5. What should professionals tell patients and their families about the usefulness of these medications and about the medication's value in various stages of Alzheimer's?

***With regard to slowing progression:***

1. What does the caregiver or person with Alzheimer's think is meant by "slowing progression of the disease?"
2. At what stage in the disease would the use of a medication be most beneficial?
3. Is there any stage in the disease when slowing the progression could be unacceptable?
4. How do you balance the values of extended life and quality of life?
5. Would you want to use such a medication to keep a loved one home longer, rather than in a nursing home?

It is important, as new drugs are studied and approved in the future, that caregivers think about what the goal is for the patient. Sometimes the end result of using a certain medication or treatment is not what the person with Alzheimer's or the caregiver may want.

As new treatments come on the market, there may be subtle forces on families to be sure their loved one receive the treatment. There are cultural norms which create expectations, even a moral obligation, that any and all treatments must be tried. But families must remember that individuals always retain the right to refuse any treatment. And if the person with Alzheimer's is not capable of expressing their views, their surrogate decision maker retains this same right.

***Choosing a Medication:***

Caregivers want to take advantage of the best treatment options available although sometimes the treatment may cause emotional and financial burdens. Clear and thorough communication between the physician and the patient or caregiver is essential in making a decision about what drug to take and for how long. While deciding on treatment options, the following are some questions to ask your physician:

- What kind of assessment will be used to determine if the drug is effective?
- How much time will pass before the drug's effectiveness can be assessed?
- How will possible side effects be monitored? What are the side effects and at what point should the physician's office be contacted?
- Is one treatment option more likely than another to interfere with medications for other conditions?
- What are the concerns with stopping one drug treatment and beginning another?

- At what stage of the disease progression is it inappropriate to continue use of any of the treatment options?
- Should we consider participating in a drug trial? What are the risks and benefits?

There are probably more questions you may want to ask to cover all circumstances of a person's treatment needs, but these may help you get the dialogue started. The answers to these questions will help you understand the options and equip you to make one of the most difficult decisions of Alzheimer's disease care.

Excerpts from: Ethical Issues in Alzheimer's disease, National Alzheimer's Association and web site at [www.alz.org](http://www.alz.org).

# WHAT CAN I DO WHEN HE/SHE...HIDES THINGS, HOARDS THINGS, STEALS THINGS?

## SOME TIPS:

- When shopping, dress them in clothing with no pockets.
- Periodically check their drawers and favorite hiding places while they are busy with another activity.
- Provide several small boxes or containers they can use to hide items. Put them on the dresser or inside a drawer. That way you can check those first.
- Never, never empty the trash without scanning it first.
- Check often for hidden food that may spoil or attract bugs.
- Don't try to change their habit of hiding or hoarding—it is a losing battle.
- If they live in a care center, let the staff know about favorite hiding places—that way they can check inside old socks first if they know that is the place glasses are often hidden.
- You might as well use the hours you spend searching for glasses, teeth or hearing aids as a time to tidy up as you go along—it makes the time spent searching seem more useful.
- Don't be upset when you realize your family member has things missing and they turn up in someone else's room—it works both ways.
- If they reside in a care center, always carry a permanent black marker in your purse so you can put their initials or name on EVERY item they have.
- Buy inexpensive items of clothing so if they are hidden or in another room, it is less of a concern.

REMEMBER...THIS TOO WILL PASS

# WHAT TO DO ABOUT HALLUCINATIONS

A person with Alzheimer's disease or related disorder is seeing, hearing, smelling, tasting or touching something that is real to them, but exists only in their mind.

They may be frightened or annoyed or amused by the hallucination.

NEVER TELL THEM THEY ARE CRAZY, STUPID OR IMAGINING THINGS!

GO ALONG WITH WHAT IS IMAGINED IF IT IS NOT A DANGER!

USE THE THREE MAIN RULES OF ALZHEIMER COMMUNICATION:

- VALIDATE AND REDIRECT
- THERAPEUTIC FIBS
- NEVER, EVER ARGUE

EXAMPLES:

Mrs. X was afraid of the red haired woman who kept looking in the windows. Mr. X calmed her by saying the woman had been hired to block-watch and protect the neighborhood. (Frightening hallucination...intervention needed...try using a therapeutic fib)

Mrs. Y loved the imagined little blond-haired girl who frequently sat on her bed and talked. For Mrs. Y it was the very best time of day. (Harmless hallucination...no need to do anything)

Mr. Z is with an imaginary tool, spending hours a day just in imaginary motions of his hands. (This is harmless...but can try redirecting into an activity using his hands that he may enjoy)

YOU CAN IGNORE HALLUCINATION IF IT IS NOT OVERLY UPSETTING.

YOU CAN TRY REDIRECTING THE PERSON TO AN ACTIVITY HE/SHE MAY ENJOY DOING

USE AN APPROPRIATE INTERVENTION IF HALLUCINATION IS HARMFUL OR FRIGHTENING.

CALL YOUR DOCTOR IF THE EPISODES ARE OVERWHELMING.

## WHAT CAN I DO ABOUT PACING?

When neurons and brain chemicals are askew, the person with Alzheimer's disease may pace for hours or days without even getting tired.

### YOU CAN:

- Make sure their footwear is comfortable
- Check often for blisters
- Make the pacing area safe
- Don't try to stop them
- Remember, this too will pass.

### EXAMPLES:

Mrs. R used a cloths line to rope off a safe pacing path for her husband. It went all around the apartment. He never tried to untie, go over, or under it. After hours of carefully observing him, she went to bed for some much needed rest, knowing he would be safe.

Mrs. R had no one to help her. If the prospect of sleeping while someone paces frightens you, then this may be the time you need to call a friend, family member or paid help or possibly think about placement in a secure Alzheimer's assisted living community.

## WHAT CAN I DO ABOUT WANDERING?

The person with Alzheimer's disease may be looking for something familiar in an unfamiliar world. It could be they are looking for a childhood home, past work place, mom or dad or children or maybe a favorite fishing hole or walking path.

They may be running away from something or someone such as an ex-mate, family members they don't like, enemy soldiers or the dangers of a prison camp.

### THINGS YOU CAN TRY:

- Re-assure them, tell them they are safe and you won't leave them alone.
- Use the three main tips for Alzheimer communication:
  - Validate and re-direct
  - Therapeutically fib
  - Never argue, they are in **their** reality, not yours.

### **Secure the house and the yard and alert the neighbors**

**Take them for a walk or drive** – they may just want fresh air and sunshine.

**Enroll them in the safe return program** at the Alzheimer's Association.

The Utah Chapter has a grant program to pay for the one time \$40 registration fee.

Call for a brochure: 801-274-1944 in Salt Lake Area or toll free 800-272-3900

# WHAT CAN I DO WHEN I LOSE MY PATIENCE?

There may be periods when the person you care for presents a behavior that may wear your patience very thin no matter how easy going or patient a person you are most of the time.

## **Understand that:**

- It is the disease, not the person doing this
- It is a malfunction in the brain
- The annoying behavior may last days, or weeks or months.
- You can re-direct, therapeutically fib and not argue until you are blue in the face with no lasting result
- You cannot change their behavior
- You can change your feelings about the behavior

***You may have reached the point where you may need to take a break or get help!***

To avoid caregiver burn-out, you need to take care of yourself. Be your #1 priority – put yourself first in order to restore patience, compassion, tolerance, equilibrium and humor.

## **Some ideas:**

1. Join a support group.
2. Give yourself private time, private space, permission to take a break/vacation, permission to not feel guilty if you do something for yourself.
3. Find an enjoyable hobby.
4. Find something funny every day.
5. Do not withdraw from your friends, your church or your favorite social organization.
6. Keep yourself groomed and be sure to exercise and eat healthy.
7. Line up a sitter, use adult day care or week-end respite in a care center to give yourself a much needed break.
8. Call the Alzheimer's Association any time to talk with someone who understands.

**Our HELPLINE is available 365/27/7**

**Call: 801-265-1944 in Salt Lake City Area or 800-272-3900 toll-free statewide**

# HOW CAN I COPE DURING DIFFICULT CAREGIVING?

Caring for someone who has Alzheimer's disease is perhaps one of the biggest commitments a person can face. It's one filled with emotional stress and hard work that can also be meaningful and rewarding.

While Alzheimer's disease usually begins gradually, it eventually causes people to become totally unable to care for themselves. As a result, your role as a caregiver may mean making significant adjustments in your life. There will be enormous demands on your time and energy. Now is the time to look at what responsibilities can be shared with others and to develop a support network that includes family, friends, outside sources and your local chapter of the Alzheimer's Association.

The following information will help you prepare for what is to come and how to cope so that you can continue to provide good care – for both the person you are caring for and yourself.

## **What are the effects on the caregiver?**

Although your situation may differ, common experiences include:

- Stress symptoms such as fatigue, stomach problems, headaches and difficulty sleeping
- Emotional symptoms such as depression, tension, anger, guilt, grief and feeling overwhelmed
- Changes in your relationship with the diagnosed person, family and friends
- Changes in marital sexual intimacy
- Financial changes brought on by the expense of caregiving and loss of income
- Feeling alone and disconnected from friends and family
- Less time for yourself

You'll probably experience different feelings at different stages of the disease. It's important that you recognize and accept that your feelings are normal and work through them. You may want to seek professional counseling, attend a support group or talk with your religious leader.

## **Why is planning important?**

Having daily and long-term plans will help you manage the needs of the person with Alzheimer's as well as your own needs. If possible, involve the diagnosed individual and other family members in planning activities and making decisions. Here are some things to consider when planning:

***Write a daily schedule:*** Establishing routines and activities will help you spend less time trying to figure out what to do and will give your loved one a sense of security and stability. Allow for flexibility and be prepared to make adjustments based on the person's changing interests and abilities. Schedule regular breaks for yourself, too.

***Identify available resources.*** Family, friends and community resources such as your local Alzheimer's Association chapter can provide help and support. Making lists of your needs will help you determine what kind of resources you will require now and in

the future. Taking advantage of these resources will help you avoid caregiver burnout.

***Become an educated caregiver.*** Obtain caregiving information from the Alzheimer's Association, government agencies, the internet and community organizations. This information can prepare you to respond to the person with Alzheimer's disease changing abilities as the disease progresses.

***Seek professional financial and legal advice.*** Planning now for legal, financial and medical needs will help you avoid rushed decisions or crises later. Discuss with an attorney or professional financial advisor issues such as durable power of attorney, advanced directive for health care, living wills, trusts and paying for care.

Your local chapter of the Alzheimer Association can help you locate which community resources will best meet your needs.

### **How can I cope?**

Learning to cope with the effects of Alzheimer's disease helps you provide the best possible care while maintaining your own health and well-being.

- Take one day at a time, but prepare for the future.
- Recognize what you can and cannot do. You can't expect to accomplish all the things you were able to do before you became a caregiver.
- Be realistic about the person's changing abilities. Hold on to your memories, but realize that the person with Alzheimer's disease now has different needs, abilities and interests.
- Understand that your relationship with the person you are caring for will be different, but it can be meaningful and rewarding.
- Learn to forgive yourself when things are not going according to your expectations.
- Find out what resources are available and take advantage of them
- Accept and ask for help of family and friends when the need arises.
- Keep your sense of humor. It will see you through difficult times and does not lessen your commitment or the sincerity of your care.
- Take pride in the care and comfort you give. Your efforts enable another person to live with dignity.
- Take time for your emotional needs. Talk with a friend or attend an Alzheimer's Association support group where you can express your feelings.

From: Especially for the Alzheimer Caregiver

# MAKING BATH TIME RELAXING

Bathing and grooming is a challenge for people with dementia and their caregivers. Hardly a support group session goes by without a caregiver asking about grooming, dressing and especially bathing issues. For the person with memory impairment bathing can be an emotionally and physically exhausting experience. It involves all parts of the body and requires a great deal of cognitive skill. For the person providing the care it can be frustrating and tiring as well.

If the person who has Alzheimer's feels confused and overwhelmed by bathing it is important to try and find out why. Is the person physically ill or feeling out of sorts? Is the person sensitive to room or water temperature? Is the person sensitive about having another present during bathing? Would the person feel more comfortable being covered up? Is the person afraid of falling? Does the water pressure bother the person? Is the person used to taking baths rather than showers, or showers rather than baths? Are you trying to bathe them too often? Could you alternate sponge baths with more complete bathing?

The caregiver needs to reasonably adapt to the patient's needs, routines and preferences. Consider past habits as well as keeping in mind that the person changes from day to day. Some days lend themselves to a more relaxed bathing experience than others. It's ok to let a few days pass by between bathing and it's ok to start the bathing process and then realize it's not a good day and complete it later or on another day. Break the bathing process into steps, for example if it's too overwhelming to attempt bathing and hair washing, wash the person's hair at another time. Or simplify the task and just use a washcloth with shampoo on wet hair after the person is already out of the shower. Wipe with clean wet washcloths as a rinse.

When bathing a person with dementia, the caregiver needs to prepare ahead for the bath, explain everything that is happening and move slowly through the process. First, select clothes and lay them out on the bed or in the bathroom, in the order they are to be put on. Prepare the bath area with flannel bath blanket on the floor or a non-slip rug and non-slip bathmat in shower to make it less slippery. Have two of everything handy, two bath towels for drying, two washcloths, and two mild soaps. As one is used, give the other to the person to hold so they can participate as much as possible. Pre-measure the no-tear shampoo and have within reach.

Make bath time relaxing and inviting. Be compassionate in your care and comfortable in assisting, respect the person as an adult, pay attention to verbal and nonverbal feedback. Calmly invite the person to take a bath or shower. Sometimes it helps to promise a special treat like cookies or ice cream for when it's over. Sometimes it helps to sing a favorite song together or play calming music.

Help to undress the person in the bathroom rather than more public areas of home. For some people, leaving a T-shirt or slip on or covering with a towel throughout the shower is comforting. Makes sure they know they are safe with you and that any part of the body they want to keep covered can remain covered while in the bath or shower. The wet article can be discretely removed during drying.

Putting a wash cloth over the shower head to soften the spray coming out will help those afraid of the rush of water. Remember, many elderly people did not take showers in their younger days, they were used to baths. Showers in general are more frightening to people with Alzheimer's disease. If a shower must be used, be sure to install grab bars and use tub seats and use hand held shower heads. If you draw a bath make sure the water temperature is to the person's liking. You may still want to use a tub seat and install grab bars and use a hand held shower head to rinse the back and wash hair.

Position yourself safely to break a potential fall if the person is unsteady. Some caregivers opt to get into the shower themselves in some casual clothing that can withstand water, to help steady the person. Avoid using bubble bath or bath oils that can make the floor slippery.

If the person wants out of the bath or shower before finished, help them out and follow the person around to complete some of the activities such as hair washing (with washcloth), tooth brushing or hair brushing. These don't have to be done in the bathroom. Be sure the person is completely dry after bathing. Check for areas of dry skin or rashes. Use body powder, cornstarch or baby powder in creases or folds of the skin and use a lotion to keep skin soft and flexible. If the attempt to groom the person becomes too distressing, you may have to stop and try again later.

Hopefully these suggestions will make the bathing experience more appealing and not so frightening. It is important that the caregiver be tuned into the person and be ready to respond. Bathing helps people feel better... it is relaxing and comforting. Often, after some gentle persuasion, when the person is in the warm soothing water, they enjoy the bathing experience.

### ***Steps to Assisting with Personal Care***

*A person with Alzheimer's disease will gradually experience difficulties with personal care tasks including bathing, dressing, grooming, toileting, eating and dental care. At first the individual may need only prompting or a little help, but eventually caregivers will become responsible for all personal care tasks. This can be very difficult for the person with Alzheimer's and may signify a loss of independence and privacy.*

*Caregivers must be aware of the abilities, fears and reactions of their loved ones in order to provide them with necessary daily care. Following are some helpful suggestions for assisting with personal care tasks:*

- *Adapt to the person's needs, routines and preferences.*
- *Help the person remain as independent as possible.*
- *Be flexible – experiment with new approaches*
- *Consider using different types of personal care products such as tooth brushes or bathing chairs.*
- *Avoid rushing the person through tasks.*
- *Pay attention to nonverbal communications*
- *Simplify instructions – use short, simple and direct words.*
- *Coach the person through each step of a task – provide encouragement, praise and reassurance.*

- *Be patient, understanding and sensitive.*

Resources:

“Steps to Assisting with Personal Care”

Alzheimer’s Association, 2003

Fact Sheet: Bathing

Alzheimer Association, 2001

# DRESSING

Physical appearance contributes to a person's sense of self-esteem. For the person with dementia, choosing and putting on clothes can be frustrating. The person may not remember how to dress or may be overwhelmed with the choices or the task itself.

There are many reasons why the person with Alzheimer's might have difficulty dressing, including the following:

## Physical Problems

- Does the person have problems with balance or with motor skills that are needed to fasten buttons or close zippers?

## Thinking problems

- Does the person remember how to dress?
- Does he or she recognize his or her clothes?
- Is he or she aware of the time of day or season of the year?

## Environment

- Is the person troubled by lack of privacy, a cold room, poor lighting or loud noises?

## Other concerns

- Are you rushing the person to get dressed quickly?
- Are you giving the person clear step-by-step instructions on how to dress or does the task seem too complicated?
- Is the person embarrassed by dressing in front of you or others?

Once you've answered these questions, you'll be in a better position to help the person get dressed.

## Simplify choices

- Lay out proper clothes for the person, including appropriate selections for warm and cool weather.
- If appropriate, give the person an opportunity to select favorite outfits or colors. Try offering just two choices of shirts or pants.
- Keep the closets free of excess clothing. A person may panic if clothing choices become overwhelming.

## **Choose comfortable and simple clothing**

- Choose comfortable and loose-fitting clothing that's easy to put on and remove.
- Cardigans, shirts and blouses that button in front are sometimes easier to work than pullover tops.
- Substitute Velcro for buttons, snaps and zippers, which may be too difficult to handle.
- To avoid tripping and falling, make sure that clothing length is appropriate.
- Make sure the person wears comfortable, non-slip shoes.
- If the person is confined to a wheelchair, adapt regular clothes to protect his or her privacy and allow for greater comfort.
- Make sure that clothing is loose fitting, especially at the waist and hips—and choose fabrics that are soft and stretchable.

## **Organize the dressing process**

- Lay out clothes in the order each item should be put on.
- Hand the person one item of clothing at a time while giving short, simple instructions such as “Put on your shirt” rather than “Get dressed.”
- Don't rush the person. Haste can cause anxiety.

## **Be flexible**

- If the person wants to wear the same outfit repeatedly, try getting a duplicate of it or have similar options available.
- It's alright if the person wants to wear several layers of clothing, just make sure he or she doesn't get overheated.
- Offer praise, not criticism, if clothing is mismatched.

# **HELPING CHILDREN AND TEENS UNDERSTAND ALZHEIMER'S DISEASE**

Alzheimer's disease is a family disease—it changes the lives of everyone it touches. Being an adult who has a parent with Alzheimer's disease is hard, but being a child in a family experiencing Alzheimer's is perhaps more difficult. When children or teens learn that a family member, friend or neighbor has Alzheimer's, they may experience a range of emotions.

They may feel:

- Sad about changes in the person's personality and behavior.
- Confused about why the person behaves differently.
- Afraid of disturbing behaviors.
- Worried that they or their parents might develop Alzheimer's.
- Angry and frustrated by the need to repeat activities or questions.
- Lonely, jealous or resentful of time and attention given to the person with the disease.

Children and teens may exhibit these emotions in ways you may not easily recognize. It is important to watch for changes in behavior that will help you to understand what they are feeling. If children and teens are having a difficult time understanding Alzheimer's disease, they may withdraw from or lose patience with the person with the disease. The emotional impact of coping with changes in family life may cause children to perform poorly in school. In some cases, stress may manifest as vague physical complaints such as stomachache or head ache. Feelings of embarrassment may cause children to stop inviting friends over to the house or to start spending more time away from home.

One of the most important things you can do for your children is to learn as much as you can about the disease. Be prepared to address questions such as:

- What is Alzheimer's disease?
- Is Grandma crazy?
- Is Grandma going to die?
- Will I get it?
- Is it my fault?
- Why can't she remember my name?
- Why does she keep asking the same thing?
- How can I help?

### **Children As Care Partners**

The impact of Alzheimer's disease on children and teens depends largely on their relationship with the person who has the disease. Most children are amazingly resilient, and the desire to relate to their loved one with Alzheimer's usually remains strong.

Because teens are at an age where they can be left at home alone and can be responsible for household chores, many teens are left to handle some caregiver responsibilities when their parents need to work or be away from home. Parents need to be aware that placing this responsibility on a teen can be overwhelming.

In spite of the challenges, adolescents who have taken on caregiving responsibilities have also reported some positive outcomes, such as feeling needed or valued,

understanding the needs of people with illnesses and having a closer relationship with the parent who is the primary care partner.

## **How Parents Can Help**

It's important to maintain open lines of communication with children and teens. Comfort and support them by offering them the opportunity to express their feelings and let them know that what they are feeling is normal. Begin the education process early and encourage them to ask questions. If your child is reluctant to talk with you, it may be necessary to seek the services of a counselor.

## **Suggestions for activities a child or teen can do with the person who has Alzheimer's:**

- Walk around the yard or neighborhood
- Look at old photographs
- Read a favorite book or the newspaper
- Watch movies or musicals
- Keep a journal together
- Create a scrapbook together
- Collect items for a Memory Box – include items important to the person with dementia.
- Write a poem together
- Interview the person about his/her life with a tape recorder or video camera
- Read out loud chapters from favorite children's books such as Harry Potter.
- Play favorite songs and sing or dance
- Look at pictures in a book

## **Tips on discussing Alzheimer's disease with a child or teen:**

- Explain in age-appropriate terms what is happening to the person with dementia.
- Give children opportunities to express their feelings and let them know their feelings are normal.
- Answer their questions honestly.
- Help them identify activities they can do with the individual with dementia.
- Be aware of signs of anxiety or stress, such as changes in behavior, poor performance in school, or withdrawal from family and friends.
- Inform teachers and school counselors of the impact Alzheimer's disease is having on your family.

# ALZHEIMER'S DISEASE AND DRIVING

## **Why driving and Alzheimer's disease is a difficult issue:**

Driving represents independence, competence and control. It's a way to access healthcare, buy necessities, be productive and stay connected to family, friends and the community. Concerns about driving often surface during the early stages of dementia when individuals are still independent and able to manage daily activities.

## **Not Like Common Changes in Later Life**

This disease is not like other changes in later life that affect driving, such as eyesight problems and slow reaction times. Many older adults who don't have dementia can assess their driving without family intervention and make gradual changes to the way they drive. And most are able to continue driving safely throughout their lives.

## **Changes in Persons with Dementia**

It's different for those with Alzheimer's Disease and other dementias. The progression of this disease is usually gradual and somewhat unpredictable. It affects cognitive functions critical to driving, such as judgement, reaction time and problem-solving abilities. It can also cause physical and sensory problems that increase driving risk. With dementia, an individual's capacity to assess his or her driving abilities may also diminish. People with dementia are especially likely to minimize the complexity of driving and overestimate their abilities. They may make excuses for their high-risk driving. Some common reasons people with dementia use to justify their continued driving include:

***"Just because I got lost doesn't mean I can't drive."***

***"I make sure I look where I'm going."***

***"I've driven many, many years and haven't had an accident."***

As driving and assessment skills decline, the risk of serious loss or injury increases. Caregivers must assume the responsibility for monitoring and regulating the driving of the person with dementia

## **Assessing concerns about driving behavior:**

Many caregivers report that they have allowed a family member with dementia to continue driving after they believed it was unsafe. At the other extreme, some family members overreact to common driving errors such as failure to complete a stop at a stop sign. They may blame these errors on the disease when the person may have exhibited this bad habit long before dementia. A single occurrence of poor driving usually is not cause to stop driving. It does, however, signal the need for increased monitoring.

These activities can help caregivers assess their concerns about the driving skills of the person with dementia:

- Create opportunities to observe the person with mild dementia while driving.
- Keep a written record of observed driving behaviors over time.
- Share observations of unsafe driving with the person with dementia, other family members and healthcare providers.

## **Monitoring Driving Behavior:**

A diagnosis of Alzheimer's disease or another kind of dementia is not automatically a reason to take away driving privileges. Unfortunately, no examination or single indicator exists to determine when a person with dementia poses a danger to himself or others. Families must determine when a person's attention span, distance perception or ability to process information makes it difficult for him or her to respond safely in driving situations.

Early warning signs of driving problems include:

- Incorrect signaling.
- Trouble navigating turns.
- Moving into a wrong lane.
- Confusion at exits.
- Parking inappropriately.
- Hitting curbs.
- Driving at inappropriate speeds.
- Delayed responses to unexpected situations.
- Not anticipating dangerous situations.
- Increased agitation or irritation when driving.
- Scrapes or dents on  
Car, garage or mailbox.
- Getting lost in familiar places
- Near misses.
- Ticketed moving violations or warnings.
- Car accident.
- Confusing brake and gas pedals.
- Stopping in traffic for no apparent reason.

Most families restrict driving after an accumulation of warning signs. Therefore, family members must frequently observe driving behaviors over time.

### **Easing the transition from driver to passenger:**

The most effective approach to limit or stop driving involves progressive steps and a combination of strategies that fit the family's circumstances, resources and relationships. For people in the early stages of dementia, driving is best reduced over time rather than all at once. Families can help by finding ways to let others drive or reduce the need to drive. Caregivers and families should be sure to address the important social needs of the person with dementia that were met through driving. When possible, include the person with dementia when planning ahead to limit driving.

Fortunately, in many cases, people with dementia begin limiting where and when they drive. The following signs indicate that a person with dementia is modifying his or her driving behavior:

- Driving shorter distances.
- Driving on familiar roads.
- Avoiding difficult unprotected left-hand turns.
- Avoiding driving at night, in heavy traffic, on heavily traveled roads or during bad weather.

### **Let Others Do the Driving**

Some people with dementia are better able to adjust to not driving if others gradually assume more of the driving responsibilities.

### **Public Transportation**

This option may work for people with mild dementia who live in urban areas and are already accustomed to using these methods. Public transportation is often too complicated for those with more advanced dementia.

Taxis can be a cost-effective alternative, especially when fares are compared to the expense of gas, insurance, taxes, repairs and car payments. Taxis could be used for people in middle to later stages of dementia if:

- There are no behavioral problems.
- The driver has explicit directions.

### **Seeking help from outside source:**

Caregivers often achieve better results by seeking support from professionals outside the family.

### **Healthcare Professionals**

Healthcare professionals may be more likely to discuss driving issues with a patient if a caregiver has met with him or her privately and shared observations of driving behavior. This input can help because physicians do not have tests to determine definitively when a person in the early stages of dementia should not drive. And some doctors may hesitate to bring up a topic as emotionally charged as not driving for fear of jeopardizing their relationship with a patient.

Doctors may request that a patient not drive for a period of time while trying new medication that may produce drowsiness. When a physician is concerned about someone's driving safety, writing a prescription to stop driving may give added weight.

### **Independent Driving Evaluations**

These assessments may be available through rehabilitation programs and some state motor vehicle departments. Driving tests are not uniform, and the evaluations vary depending on the extent of the tests and the evaluators' familiarity with cognitive impairments and other conditions that affect driving. Nevertheless, such tests may provide families additional input and support. Healthcare professionals may know how to arrange for an independent driving evaluation.

### **Other Sources of Support**

Lawyers, financial planners and care managers may be in a position to raise questions

about driving safety. Caregivers can enlist their assistance by asking them to mention the subject as part of planning. Alzheimer's support groups offer opportunities for caregivers and persons with dementia to share concerns and explore options.

### **Understanding how family relationships affect the decision:**

***“There are six of us in the family – some still deny there is a problem, some tend to panic and the rest of us feel caught in the middle.”***

No two families dealing with dementia resolve transportation issues in exactly the same way. Roles and relationships within families can affect decisions about when and how a person should stop driving. Individual responses of family members may vary. For example, a caregiving spouse may try to protect the person with dementia by withholding information about driving incidents from adult children. An adult child may intervene on matters of safety, even though this might affect the relationship with the parent. One person may avoid confronting the driving concerns of the family member, while another may take charge of the situation and act without input from others.

Caregivers need to remember that family members follow long-established patterns for making decisions. It is unrealistic to think that patterns will change when handling a difficult issue like driving safety. Caregivers can work to minimize friction by listening to different opinions and appreciating what each person can contribute, even if it differs from their point of view.

Disagreements in families are often the result when individuals do not have the same opportunities to assess driving abilities. Having factual information about driving behavior does not guarantee families will reach consensus on when to limit driving. However, frequent, open communication about specific, observed behaviors and concerns may help to lessen differences. Everyone involved in caring for the person with dementia can help by focusing on the key issues – the self-respect of the person with dementia and the safety of everyone on the road.

### **Advice from caregivers who made this decision:**

Caregivers who have wrestled with driving and transportation issues were asked: “If you could do it over, what would you do differently? What advice would you give others who are in similar situations?” They revealed four basic principles that can help caregivers and people with dementia manage driving and transportation decisions.

#### **1. There is no easy answer; no *right way*.**

Caregivers need to consider the personality and the abilities of the person with dementia when making decisions over the course of the disease. They must take into account the roles and relationships within the family that affect decisions and their outcomes. Each family must select strategies that will work within its unique situation.

#### **2. Begin discussions and planning early and involve the person with dementia.**

Ideally, a person with dementia should make the transition from driver to passenger over a period of time. Open, early and continual communication can help the person with dementia and the family to agree on a course of action before a crisis occurs.

#### **3. Base decisions on driving behavior observed over a period of time.**

Regular monitoring and assessing of driving helps caregivers respond appropriately. A diagnosis alone may not be sufficient reason for a person to stop driving.

However, when it clearly is no longer safe for a person to drive, caregivers must not delay in taking necessary steps. In hindsight, many caregivers regret permitting a loved one to drive longer than it was safe. The result was prolonged anxiety for caregivers and placing others at risk.

**4. Get support when making and implementing decisions about driving.**

It is not healthy for the caregiver, the person with dementia or the family as whole, when one person shoulders all of the responsibility for making and implementing decisions about driving and dementia. Caregivers can make reasonable requests of family members and those outside the family. Neighbors, friends and relatives can contribute by providing for the emotional, social and transportation needs of the person with dementia.

Doctors, lawyers, care managers, financial planners and local Alzheimer's support groups offer information, guidance and perspective. People in authority outside the family can reinforce the family's efforts to ensure the safety and dignity of a person with dementia. The more people who are asked to help, the less any one person has to do and the greater the likelihood that the person with dementia will get the best support.

# PLANNING FOR THE HOLIDAYS WHEN ALZHEIMER'S IS PART OF THE FAMILY

The holidays are traditionally times when we gather together with family and friends for sharing fond memories, laughter, good food and fun times as we enjoy old and new rituals together. But for families coping with Alzheimer's disease the holiday season can be stressful; filled with disappointment, sadness, frustration and guilt.

Caregivers may feel overwhelmed in their effort to maintain holiday traditions on top of caring for the person with Alzheimer's disease. Caregivers may also feel hesitant to invite family members and friends over to share the holiday, for fear they will react negatively to the changed behavior of the family member with Alzheimer's disease.

If just before a holiday celebration you feel guilty, angry, frustrated or trapped, it may help to know that these feelings are normal and that you are not alone. Here are some suggestions that may help to ease the burden of care giving and help make the holidays a happy time with many memorable moments.

- Discuss holiday celebrations with relatives and close friends. Make sure that family members understand the situation and have realistic expectations.
- You may want to familiarize others with the situation by composing a letter that makes these points:
  - "I'm writing this letter to let you know how things are going at our house. While we are looking forward to your visit, we thought it might be helpful if you understood our current situation before you arrive.
  - You may notice that \_\_\_\_\_ has changed since you last saw him/her. Among the changes you may notice are \_\_\_\_\_. I've enclosed a picture so you know how \_\_\_\_\_ looks now.
  - Because \_\_\_\_\_ sometimes has problems remembering and thinking clearly, his/her behavior is a little unpredictable. Please understand that \_\_\_\_\_ may not remember who you are and may confuse you with someone else. Please don't feel offended by this. He/she appreciates you being with us and so do I. Please treat \_\_\_\_\_ as you would anyone else. A warm smile and a gentle touch on the shoulder or hand will be appreciated more than you can know. I would ask that you call before you come to visit or when you are nearby so we can prepare for your arrival. Care giving is a tough job and I'm doing the very best I can. With your help and support, we can create a holiday memory that we will treasure."
- Give yourself permission to do only what you can reasonably manage. Reduce obligations and delegate details whenever possible. If normally you invited 15-20 people to your home, consider inviting five for a simple meal. You may also want to ask others to bring dishes for a "potluck" meal or to host the meal at their home. Choose to participate in only the activities that are comfortable for you. Learn to say "no."
- Realize that this holiday may be unlike the holidays of the past. You can build on past traditions and memories--your family member may find comfort in singing old

holiday songs and hymns and the reading or telling of traditional stories. But also experiment with new holiday traditions, such as renting seasonal videos that a less active person may enjoy.

- Maintain your normal routine as much as possible to reduce confusion. Taking on too many tasks will tire both you and the person with Alzheimer's disease. Try to blend seasonal rituals into the daily activities that you both depend upon, such as taking a relaxing walk outdoors.
- Use holiday preparation activities as opportunities to spend quality time together. You may want to begin slowly by asking the person with Alzheimer's disease to help you prepare food, wrap packages, hang decorations or set the table. People with Alzheimer's can become disoriented by blinking lights or by decorations that change the look of their environment. Avoid using candles and stay away from decorations such as artificial fruits that could be mistaken for edible treats.
- Caregivers know best what their loved ones with Alzheimer's disease are capable of doing. If you are caring for your loved one at home, try reminiscing about people on your holiday card list, read cards you receive together, talk about favorite holiday foods, sing holiday songs, take a drive around town to view holiday lights and decorations. When possible, involve small numbers of family and friends in these activities.
- Encourage useful gifts. Among the practical, useful gifts for people with Alzheimer's disease are: identification bracelets, comfortable easy to remove clothing, audiotapes of favorite music, videos of family members, photo albums, subscriptions to magazines or cable television, large piece puzzles, video of an old favorite movie, simple story books with pictures, bird feeder for outside the window, lap blanket, body lotions, music box that plays a favorite tune.
  - (Warn people about difficult or unsafe gifts. Advise people not to bring dangerous tools or instruments, challenging board games, complicated electronic equipment or pets.)
- Try to be flexible. Consider celebrating over a lunch or brunch, rather than an evening meal, if the memory impaired person is confused in the evening. Refrain from serving alcoholic beverages and keep the room bright.
- Keep taking good care of yourself. Don't neglect your own needs. Get adequate rest and exercise. If friends and family ask what you want for a gift, suggest a gift certificate to a carryout restaurant, laundry or dry cleaner, or cleaning service.
- Be gentle with yourself. Don't be afraid to cry as you celebrate years past and create new traditions and memories this year.
- Ask for help and support. Develop a bulletin board for listing tasks and responsibilities. If someone asks, "What can I do to help?" you can respond with a specific idea. Maximize any opportunity you have to make holiday celebration easier on yourself so that you can concentrate on enjoying time with the people you love.

- *With some advance planning you can have an enjoyable holiday season*

**Resources:**

“Home for the Holidays” Alzheimer’s Association of the California Council

“Celebrating the Holidays” Fact sheet, Alzheimer Association, Utah Chapter

# HOME SAFETY FOR PEOPLE WITH ALZHEIMER'S DISEASE

## Is it safe to leave the person with Alzheimer's disease alone?

It will be necessary to evaluate this issue often throughout the course of the disease. Does the person with Alzheimer's disease...

- Display confused and unpredictable behavior under stress?
- Recognize dangerous situations such as fire?
- Know how to use a telephone when necessary? Knows their address and phone number?
- Know how to get help? Can they dial 911? Use a personal emergency response system?
- Become restless or show signs of agitation or depression if left in the home alone?
- Wander and become disoriented throughout the day or in the evening?
- Attempt to do activities that may need supervision such as cooking, repair, woodwork?

## Tips for Creating a Safe Environment:

Make sure that all areas which are accessible to the person with Alzheimer's disease are safe and dangerous areas are difficult to access:

### Kitchen:

- Lock up cleaning supplies with childproof latches on storage cabinets and drawers.
- Turn off electricity to the garbage disposal. People with Alzheimer's may put in unwanted objects or even their hands. Place a drain trap over drains so unwanted items will not be washed down the drains.
- Hide knives, scissors, blades and other utensils that may be sharp or dangerous.
- Put away the toaster, blender and any small appliances that may be difficult or dangerous to use.
- Unplug larger appliances such as the microwave if not safe to use unsupervised.
- Remove knobs from the stove or have a switch installed to turn stove off or disable the stove completely.
- Keep a fire extinguisher nearby. Do not store flammable liquids, matches or lighters in the kitchen.
- Clean out refrigerator regularly. People with Alzheimer's do not know if food is fresh or spoiled.
- Remove all artificial fruit and vegetables or food shaped magnets because they may appear to be edible.
- Remove throw rugs to avoid tripping.

### Bathroom:

- Set water temperature at 115-120 degrees to avoid scalding.
- Install grab bars in contrasting color (or cover with colorful tape) in tub/shower and beside toilet. Use an elevated toilet seat. Use plastic shower stool and hand-held showerhead to make bathing easier.
- Apply textured decals on slippery surfaces. Remove area rugs and replace with washable wall-to-wall carpeting to avoid slipping.
- Supervise the use of hairdryers, electric and hand razors and curling irons or if the person cannot use appliances even with supervision, cover electrical outlets and remove appliances from bathroom.
- Remove locks from the bathroom door. Do not leave a severely impaired person with Alzheimer's disease alone in the bathroom.
- Discard dangerous items from the medicine chest. Store medications (prescription and nonprescription) in a locked cabinet. Supervise the taking of prescription and over-the-counter medications.
- Remove cleaning products from under the sink and lock away.

### **Bedroom:**

- Install night lights between bedroom and bathroom.
- Monitor the use of heating pads, which can cause burns. Keep controls out of reach. Avoid using electric blankets. Avoid space heaters and portable fans.
- Place bed against wall for increased security or place mattress on floor if necessary to prevent falls.
- Use an infant intercom to alert you to any noises to indicate need for help.

### **Garage and outside the house:**

- Put away power tools such as drills, saws and other tools such as axes and picks. Limit access to large equipment such as lawnmower, edger and snow blower.
- Lock up poisonous products such as paints and fertilizers. Remove and lock up all fuel sources and fire starters for grills when not in use.
- Store car keys in a secure location not visible or accessible to the person.
- Lock up gates and fences...disguise outdoor locks or install deadbolts on gates. Prune bushes and foliage well away from walkways and doorways. Make sure outdoor lighting is adequate.
- Always supervise person in areas that are not enclosed.
- Keep steps textured to prevent falls when wet or icy. Keep handrails in good repair. Mark the edges of stairs with bright paint or reflective tape. A ramp to the home may be needed instead of using stairs. Eliminate all uneven surfaces and obstacles such as hoses, to prevent falls.

### **Throughout the home:**

- Remove poisonous plants. Check with poison control if needed.
- Apply colored decals to large windows and sliding glass doors.
- Avoid clutter...it creates confusion and danger.
- Keep all alcohol locked in a cabinet. Drinking alcohol can create confusion and will interact with some medications.

- Stairways should have a handrail that extends beyond the first and last steps and be carpeted or have safety grips.
- Install smoke alarms near all bedrooms and check their function and batteries regularly.
- When care giver is not home, use a telephone answering service or machine and turn phone down. The person with Alzheimer's may not be able to take a message and may be a target for telephone exploitation by solicitors.

# MEALTIME TIPS

Good nutrition is important for the person living with Alzheimer's disease. Eating properly keeps the body strong and healthy. It is not yet known if a proper diet affects the progress of dementing diseases, but it is known that forgetful people often fail to eat properly and can suffer nutritional deficiencies. Weight loss happens all too quickly for people with dementia.

Because Alzheimer's disease attacks the brain, the affect can be noticed in all body systems, including the physical process of eating. A person with Alzheimer's disease may not realize what hunger feels like and forget to eat...or they may forget that they just ate and want to eat again. Sometimes they may not feel hungry and become confused as to the timing and purpose of meals. They also deal with the loss of taste and smell and may not find food appetizing anymore.

The process of eating becomes complicated. Utensils may be difficult to identify and confusing to use. Sometimes the Alzheimer person doesn't know what to do with the food in front of them, especially when there is more than one plate with food on it or more than one glass with drink. If they are alone they may hide food, throw food away, or eat it after it has spoiled.

Proper nutrient and fluid balance is necessary to control some of the behaviors that Alzheimer's disease can cause. Poor diet and/or dehydration can worsen confusion. It is very important to pay special attention to mealtimes. The following mealtime tips may help:

## **Calm Mealtimes**

Serve meals in a quiet environment away from the television and other distractions. Keep the table setting simple, place only the utensils needed to eat the meal and avoid placing other objects on the table that might distract or confuse the person. Sometimes quiet, slow, soothing music is helpful. Make sure the room is not too hot or cold. Fussy and messy eaters do better when the environment is calm and comfortable.

## **Consistency**

Routine is important for people with Alzheimer's disease. Meals should be served at the same time every day and in the same place with the same prompts and without confusion. Be realistic about going out to eat. Avoid noisy or large restaurants; choose those that are small, comfortable and familiar. Decide if the person can order directly from the menu, or if you want to order for the person.

## **Regularity**

People with dementia develop rigid likes and dislikes and refuse to eat certain foods.

If a person has a favorite food, try to serve that food often as long as it's nutritious. If the person has never liked a certain food, they will not like it now. New foods may confuse the memory impaired person. If the person insists on eating only one or two things, discuss this with the doctor so the dietary supplements or vitamins can be added.

## **Simplicity**

Offer just one food at a time. Individuals with memory loss are often unable to decide among the foods on their plate. Serving only one or two foods at a time takes away the stress of having to decide what to eat. For example, serve only a salad, then only the mashed potato, then the meat dish etc. Serving food on brightly colored plates helps increase intake. On a bright red or blue plate the Alzheimer person can see the contrast between the food and the plate making the food easier to pick up, food seems to disappear on beige or light colored plates.

If utensils are too complicated, try finger foods that are easy to pick up. There is nothing wrong with putting mashed potatoes on a slice of bread to pick up and eat. This is also good for people who are unable to sit still long enough to eat... they can pace and eat at the same time. Avoid distractions and choose foods that will attract the person's attention. Make sure the food is cut into bite size pieces that are small and tender enough to be eaten safely; people with dementia often forget to chew food properly. Make sure the food is not too hot.

### **Company**

Sit down at the table with the Alzheimer person and eat your meal at the same time. When the person with memory loss sees you eat, it may be enough of a cue to prompt them to eat as well. If you need to spoon feed the person, put only a small amount of food on the spoon at a time, wait until the person swallows before giving more. You may have to tell the person to swallow, because sometimes they forget and will carry the food around in their mouth. If the person does have trouble swallowing, be sure to offer soft foods that do not require much chewing, such as chopped meat, gelatin and thick liquids.

### **Stimulation**

Provide cues that will indicate to the Alzheimer person that it is meal time...the sight and sounds of the dining room table being set with dishes and the activity in the kitchen can cue the person that it is mealtime. Fragrant foods like popcorn or baking bread can stimulate the body to feel hungry. Rituals such as washing hands and putting on an apron can be good cues as well.

### **Fluids**

Dehydration can cause remarkable loss of cognition. Make sure that the person gets enough fluid each day. Even mildly impaired people may forget to drink. Inadequate amounts of fluid can also cause physical problems such as urinary tract infections. Be careful to check the temperature of hot drinks since the person with memory impairment may lose ability to judge temperature and burn themselves. If the person does not like water, offer flavored drinks and juices. Avoid more than one cup of coffee, tea or caffeinated colas. Caffeine is a diuretic and takes fluid from the body.

**Minimize Swallowing Problems.**

If swallowing becomes a problem, avoid foods such as nuts, popcorn and raw carrots, which may get lodged in the throat. Instead, grind foods or cut them into bite-size pieces. Serve soft foods such as applesauce, cottage cheese and scrambled eggs. Serve thicker liquids such as shakes, nectars and thick juices or serve a liquid along with the food. Gently explain that the person should chew the food, eat slowly and swallow.

Be sure to be patient with the memory impaired person. Don't criticize the person's eating habits or urge him or her to eat faster. Be sure to give the person the opportunity to eat with other family members for as long as possible. Make mealtimes a pleasant but simple event.

# SLEEP AND ALZHEIMER'S

Alzheimer's disease and sleep often times don't mix. Over 90% of persons with dementia experience sleep problems such as too much or too little sleep, waking up repeatedly, changes in sleep cycles and daytime napping. While similar changes occur in the sleep of older people in general, these changes occur more frequently and tend to be more severe in persons with dementia. The "internal" clock within the brain seems to be damaged by the disease. To make matters worse, sleep disturbances further impair memory and cognitive functioning.

Often time people with Alzheimer's disease may wake at night and wander around the house, get dressed, try to cook, or even go outside. They may see things or hear things that are not there. Older people do not see well in the dark and that may add to their confusion. They may misinterpret what they see and think they see people or think they are in an unfamiliar place. This may cause them to panic.

There are things that can be done to reduce this type of night time behavior before having to rely on medications for sleep. The following suggestions may help to improve sleep routine, sleep environment and reduce daytime sleep:

- Make sure that the person with Alzheimer's disease gets enough bright light during the day, especially in the late afternoon/early evening. A nice long walk in the afternoon in fresh air and sunshine can make a world of difference.
- Avoid daytime naps if the person is having trouble sleeping at night. Provide regular activities to keep the person occupied, awake and active during the day so that napping can be avoided and the sleep cycle does not get reversed. A day care center is one of the best ways to keep a person active during the day
- Make afternoon and evening hours less hectic. Schedule appointments, trips and activities such as baths or showers early in the day. If the person does not like changing into bed clothes for the night, keep them in comfortable clothes for the day and allow them to sleep in them if need be.
- Help the person to use up extra energy through exercise. For the person who tends to pace or wander in the evening, you may want to arrange at least one or two brisk walks during the day. Engage in regular daily exercise, but no later than four hours before bedtime.
- Maintain regular times for going to bed and arising. Keep these regular hours even when traveling or during holidays.
- Establish a comfortable, secure sleeping environment. Attend to temperature and provide nightlights and/or security devices. Reduce the level of noise from radios, televisions or stereos, control the number of people who visit in the evening hours, or confine noisier family activities to another area of the house.
- Discourage staying in bed while awake during the day; use the bedroom only for sleep.

- If the person awakens, discourage watching television. Reassure and comfort the person...speaking softly and quietly. Gently remind the person that it's nighttime and that they need to go back to bed. Maybe a warm cup of milk will help calm the person, or playing some quiet music. Tell the person experiencing sleeplessness that you're there and will remain close by as they go back to sleep.
- Establish regular meal times. Control the person's diet. Reduce foods and beverages with caffeine (chocolate, coffee, tea, soda) or restrict them to the morning hours to reduce agitation and sleeplessness. An early dinner or late afternoon snack may also help. Avoid alcohol and nicotine.
- Avoid excessive evening fluid intake close to bedtime. Make it easy for the person to use the bathroom. Keep a night light on or put reflective tape around the bathroom door. Consider a bedside urinal or commode. Remember to encourage the person to use the bathroom before going to bed.
- People with Alzheimer's may find it difficult to sleep in their beds, they may fall asleep more easily on the living room couch or in a reclining chair. Give them a pillow and blanket and let them sleep! It's easier to let them sleep there than be up all night arguing about it.
- Administer drugs that may have a stimulating effect no later than six to eight hours before bedtime. If the person is taking cholinesterase inhibitors (Aricept, Exelon or Reminyl) avoid nighttime dosing
- Consult with your physician. Your physician may be able to prescribe medication to encourage sleep. At the same time, your physician can check for signs of depression or physical problems such as prostate difficulties or urinary infection that might lead to frequent urination. This condition can cause pain and make sleep uncomfortable. Treat any pain symptoms

Drug therapy should be considered only after a non-drug approach has failed and reversible medical or environmental causes have been ruled out. The risks of sleep-inducing medications for older people who are cognitively impaired include: increased risk for falls and fractures, increased confusion, and decline in the ability to care for themselves. If sleep medications are used, an attempt should be made to discontinue them after a regular sleep pattern has been established.

Using sedatives-hypnotics to induce sleep for an Alzheimer patient can be difficult. Sedatives affect the chemistry of the brain and since the brains of Alzheimer patient's are more sensitive, it may be difficult to find the right drug in the right dose without causing more confusion or in some cases, make sleep patterns even worse. The doctor may have to try several different medications or several different nightly dosing schedules until the right medication and dose for the person is found.

Make sure you, the caregiver, get adequate rest. Just because the person with Alzheimer's can't sleep at night doesn't mean you should go without sleep. Arrange for another family member to supervise the person at night. Or arrange the room so that it is safe enough (has a locked door and locked windows) to let the person stay awake

and pace there while you nap or sleep in another room. Just remember, periods of restlessness and sleeplessness is an unavoidable part of Alzheimer's disease. The person is not trying to rob you of your sleep deliberately!

Resources:

The 36 Hour day by Nancy L. Mace, MA and Peter V. Rabins, M.D.  
Alzheimer Association Fact Sheet: Sundowning

# SUNDOWNING---WHAT TO DO

People with diseases such as Alzheimer's often have behavior problems in the late afternoon and evening. They may become demanding, suspicious, upset or disoriented, see or hear things that are not there and believe things that aren't true. Or they may pace or wander around the house when others are sleeping. Common symptoms of sundowning include:

- Anxiety
- Fear
- Disorientation
- Repetitive questioning
- Verbally abusive behavior
- Wanting to go home

While experts are unsure how or why this behavior occurs, they suspect that the problem of late afternoon confusion, which is sometimes called "sundowning" may be due to these factors:

- The person with Alzheimer's can't see well in dim light and becomes confused.
- The impaired person may have a hormone imbalance or a disturbance in his/her biological clock and therefore suffers from disruption of nighttime sleep which causes tiredness.
- The person with Alzheimer's tires at the end of the day and is less able to cope with stress.
- The person is involved in activities all day long and grows restless if there's nothing to do in the later afternoon or evening and can also sense lack of companionship and emotional support during nighttime hours.
- The caregiver communicates fatigue and stress to the person with Alzheimer's and the person becomes anxious.
- Possible hunger and thirst or need to go to the bathroom.

Try these ways to lessen the behaviors of "sundowning":

- A hearty snack as soon as sundowning starts.
- A walk if you suspect excess energy. Make sure they get at least 15 minutes a day of outdoor activity and possibly sunshine.
- Schedule calming activities for the time of day agitation usually starts.
- A nap if you think the person may be overly tired in the early evening hours.
- Turn on lights to hide the fact that the sun is setting.
- Turn off the TV, cover mirrors and ask visitors to leave if agitation is severe.
- Offer their favorite activities if you suspect boredom; look at old photographs, take a walk, create a "sensory" box or basket to rummage through.
- A calming herbal tea or cocoa, or dish of ice cream.
- Reassure them and let them know you will be there for them.
- Act in a calming manner with friendly smiles and warm caring touch.
- Ask the doctor for suggestions/guidance if medical intervention is needed.



## VACATIONING

When summer comes, many families make plans to take a vacation to a fun place or just to relax and have a change of scenery. If you are a caregiver of a family member with Alzheimer's disease then you will have to make appropriate plans based on the stage of the person's memory loss. The impairments caused by the disease may affect traveling and make the trip difficult, not only for the person suffering memory loss, but also for the caregiver and other family members.

In general, vacations do not "relax" a person with Alzheimer's disease nor does he or she necessarily return "better off." The person with Alzheimer's disease usually forgets the vacation experiences immediately upon return home. Many people with Alzheimer disease will ask when it is time to go home as soon as they leave their permanent home. Strangers, foreign languages, customs, food, water, accommodations, climates, time changes, busy terminals, planes, trains and buses are all known to precipitate catastrophic reactions in the Alzheimer's disease person. In fact, many families first notice the person's symptoms on a vacation.

If the vacation that is planned is too difficult for the person suffering memory loss then respite is available at most Alzheimer assisted living facilities. The family member can be checked in to spend their "vacation" for several days or longer depending on availability. They will have their own room, be part of the Alzheimer assisted living community, be under 24 hour care and be able to participate in the facility's activity programs until the caregiver returns from their trip. Respite care can also be arranged in the home through one of the many agencies that provide senior care services. Call the Alzheimer Association for referrals.

If the decision is made to take the family member with Alzheimer's disease on vacation then the following *Action Steps* from the Alzheimer Association will be helpful:

### ***Plan a manageable vacation.***

- Think about your expectations. If you choose to travel with the family member, you will have many of the same responsibilities you have at home. In that sense, this will be a "working" vacation.
- Stick with the familiar. Consider vacationing in ways the person was accustomed to before the onset of the disease, e.g. if the person has never traveled by airplane, it would probably be better to drive.
- Stay away from busy places or from situations that may cause over-stimulation or anxiety. Large cities such as New York, Chicago, or Los Angeles might make the person more confused or anxious. Large amusement parks might pose a problem. Visiting a relative with a large, noisy family may not be very relaxing as well.
- Keep your vacation simple. Avoid fast-paced sightseeing trips. Make as few changes in scenery as possible. Escorted tours with people you know and understand your caregiving responsibilities may be enjoyable.

- Consider a short trip, especially if you are unsure how the person will react to traveling.
- Choose a “fail-safe” option. Pick a vacation package that allows you to leave early—without financial penalty—if the person becomes ill or wants to return home.
- Develop a list of destinations and contact information for family members at home. Also make a list of medical professionals along your travel route for you or your travel companion.

***Consider the needs and safety of the person with Alzheimer’s disease.***

- Advise airlines, hotels or tour operators that you are traveling with a person who has memory impairment. You may want to reserve a wheelchair or plan special meals during an airplane flight. Let tour guides know that the person cannot be left unattended.
- Prepare identification items. Make certain that the person wears an identification bracelet or clothing tag with his/her full name and your name. Keep all credit cards, travelers’ checks and passports with you for security. Bring insurance cards, medication records, and a list of medical problems.
- **NEVER LEAVE YOUR MEMORY IMPAIRED TRAVELING COMPANION ALONE!** If you are on a tour with friends or relatives, then you may be able to occasionally rely on them. **NEVER** ask a stranger to watch the person. Someone who is not familiar with the effects of the disease may not know what to do in a difficult situation. Prepare a small card to hand to staff of restaurants or shops that states your travel companion has memory problems and may have difficulty finding the right words or understanding and/or may display occasional unusual behavior: frank, discrete disclosures to tour guides and other travelers will save frustration and embarrassment.
- Take security precautions. If traveling by car, automatic locks are useful. You may want to remove the locks from his/her side of the car to prevent opening the door while driving. In most cases, the person should sit next to the driver and not in the back seat. Automatic windows may be dangerous-- you may want to lock the windows.
- Prepare your traveling companion. Telling your traveling companion about the trip in advance may help him/her feel part of the decision-making process. On the other hand, you may only want to inform him/her shortly before leaving with a simple explanation: “We’re going on a trip together to California; I’m going to start packing some of your things. Can you help me pack this suitcase?” You may also find it less disruptive simply to announce your plans on the day you are leaving.
- Time your travel. If she/he travels better at a specific time of the day, you may want to make plans accordingly. Take breaks along the way--offer fluids and snacks constantly.
- Anticipate and avoid delays. If you are traveling by train, bus or plane, have a friend drive you to the departure point to relieve you of parking the car and handling

the luggage. Call ahead to determine if your departure will be delayed. (Many people find it disturbing to wait for hours in crowded terminals.) Bring along items such as magazines, audiotapes, or a deck of cards to entertain and relax your traveling companion.

- Plan ahead for rest room use. If the Alzheimer person is a man and you are a woman, or vice versa, you may want to bring along a friend or family member who can help or ask a staff member to accompany him/her into the public rest room. Once aboard the train or plane, see if you can accompany him/her to the rest room. Take an "Occupied" sign with you to use if your assistance is necessary. It may also be helpful to provide extra protection by using adult incontinence products.
- Allow for extra time. Avoid the temptation to cram several activities into one day. Instead, plan for a single activity and have a couple of alternatives in mind if there is extra time available. In addition, you and your travel companion may need more time in between activities to relax and rest.
- Maintain familiar eating patterns and times. Find quiet restaurants or use room service. Also, order the same types of food at the same time of day as you would at home.
- Maintain daily routines e.g. if the person showers every morning, you should try to maintain that routine.
- Have faith in your own knowledge, judgment and experience. No one knows the individual better than you do. While a growing number of tour operators have oriented their employees in dealing with persons with dementia, you understand best what does and doesn't work. Have confidence in your abilities and in your loving concern as a caregiver.

Enjoy your special time together and remember to take many pictures. The person with Alzheimer disease will enjoy the pictures and your stories about them much longer than his/her fading memory of the trip.

*Resources:*

Adapted from the Alzheimer Association Action Steps hand out. Primary resource for the action steps fact sheet was Liz Kendall, R.N., B.S.N., Caregiving Program specialist, Center on Rural Elderly, University of Missouri, Kansas City, MO.

Traveling with the Alzheimer Disease Patient: To Go or not To Go???? By Lisa Gwyther, MSW (from "The Caregiver" Newsletter)

# VISITING THE PERSON WITH ALZHEIMER'S DISEASE

Visitors are important to people with Alzheimer's disease. They may not always remember who the visitors are, but they will be responsive to the human connection and socialization. When planning a visit to a person with Alzheimer's disease you may want to consider the following things:

Plan the visit at the time of the day when the person is at his or her best. Usually mid-morning or early afternoon is a good time with evening not being the best time.

Possibly bring along some kind of activity such as something familiar to read or photo albums to look at. Thinking and talking about the past can be comforting and enjoyable for a person with Alzheimer's disease. But you must also realize that the person may not want to do your planned activity...then be flexible and ready to just spend some quite time or maybe do something active like going for a walk together.

Be calm and quiet. Avoid using a loud tone of voice. Do not talk to the person like you would to a child but talk with respect and kindness. Be comforting and reassuring and let the person know it's ok if he/she is having difficulty expressing himself or herself. Show that you are interested and keep listening and maintaining eye contact. Look for the feelings behind the words. Many times, it's how something is said rather than what is being said.

Respect the person's personal space. Don't get too close or touch the person unless you have asked permission to do so. If you do get permission to give a hug or hold a hand, then by all means do so, because people with Alzheimer's disease often do not get much physical contact.

Try to establish eye contact. Bend down or sit down in order to meet the person at eye level. Do not stand up and look down at the person while speaking.

Call the person by name to get his or her attention. Do not use endearments unless you know the person well or they are a family member and this is acceptable to them. Their name is usually well recognized, endearments are not.

Remind the person who you are if he or she doesn't seem to recognize you, tell them your name and your connection to the person or family. If they still don't know who you are, that's ok, just continue with the visit as someone who cares about them and wants to spend time with them.

If the person is confused, don't argue or try to correct what they are saying. Respond to the feelings being communicated. If they are becoming agitated, distract the person with a new subject to talk about or redirect by offering a sweet treat or help with a favorite activity.

Repeat a sentence if necessary and allow plenty of time for comprehension. They may ask the same thing over and over believing it's the first time they've asked. They cannot remember that they cannot remember. Be patient and cheerful and reassuring and pretend that each time they ask is their first time and answer kindly.

If the person does not recognize you or is unkind or responds angrily, remember not to take it personally. He or she is reacting out of confusion. Be generous and gracious in your understanding, the person with Alzheimer's disease and their caregiver will appreciate your efforts.

## REMINISCING

Thinking and talking about the past can be comforting and enjoyable for a person with Alzheimer's disease. Celebrating special occasions is also a good way for people to share special moments and bring up memories of the past.

Holidays can bring joy and meaning into the life of someone with Alzheimer's disease. They may remember holidays of long ago and wish to share those memories with you. They can also stimulate a wide variety of senses when you incorporate traditional holiday music, food and decorations to bring out the flavor and traditions of the holiday. Ask the person with Alzheimer's disease for help when preparing for the special day.

Go beyond celebrating major holidays and find ways to enjoy some days you may not have acknowledged before such as Arbor Day, Columbus Day, Flag Day or May Day or make up your own day. Plant a tree, read about Columbus, make a May Day basket or make a treat for their own special made up day.

Birthday parties are exciting for the person with memory loss. These celebrations bring people together and the person with Alzheimer's disease can enjoy being a very special part of a family or a group. So make a big deal out of his/her birthday and use the opportunity to reminisce with him/her about past birthdays.

Taking digital photos or instant photos, such as Polaroid, is a great way to involve someone in an activity and capture the moment as it happens. Photos are enjoyable for the person with memory loss to look at and can reinforce visual skills. Taking photos outside also incorporates a bit of exercise and adventure when exploring different parts of the neighborhood, park or garden.

Put photos that you take in an album. Start by having the person with memory loss sort the photos and allowing them to enjoy them before putting them in an album. Sorting photos taken a long time ago can trigger memories and reminiscing. Organizing photos is a pleasurable activity that also stimulates visual and motor skills.

A person's work identity, whether he/she was an executive, homemaker, bus driver, doctor, or police officer, is important to the person's identity. One of the most upsetting tolls of Alzheimer's disease is the loss of a work identity, even if the person has been retired for a long time. But the skills can still be recalled in small ways. For example, create a designated "office space" for the person. Set up a calculator, notebook on a desk on certain days. If the person was a beautician, you could set up a workstation with combs, brushes and curlers and some wigs to work on.

Remember fashions can transport us back in time. Fashions may remind us of what we were doing in the past or reflect what was happening in the world. Pictures of women/s, men/s and children/s clothing found in old books or vintage retail store catalogs may remind a person with memory loss about his/her past.

Watching old movies or television shows can be fun, relaxing way to old memories, encounter familiar stories and get visual stimulation. It can also provide a great topic for conversation

People with Alzheimer's disease sometimes live in the past. Reminiscing about past events or their young adulthood or childhood can be a pleasant way for them to experience old memories, use verbal skills and connect to others socially. Talking about events and people they remember might even stimulate them to remember more about their lives. Reminiscing is an important part of the lives of those who have memory loss and an excellent activity to do when visiting.

# 101 THINGS TO DO

## Activities to do with People who have Memory Loss

1. Clip coupons
2. Sort poker chips
3. Count tickets
4. Rake Leaves
5. Use carpet sweeper
6. Read out loud from:  
*Good Old Days*  
PO Box 9001  
Big Sandy, TX 75755-9001
7. Bake Cookies
8. Look up names in phone book
9. Read daily paper out loud
10. Ask a friend, neighbor, congregational acquaintance who has a baby or younger child to visit.
11. Listen to polka music
12. Plant seeds indoors or out
13. Look at family photos
14. Toss a ball
15. Color pictures
16. Make homemade lemonade
17. Wipe off the table
18. Weed the flowerbed
19. Make cream cheese mints:  
2 lbs powdered sugar  
8 oz cream cheese  
2 drops peppermint extract  
Food coloring as desired  
Knead together and press into mint molds
20. Have a spelling bee
21. Read from:  
*The Reader's Digest*  
*Pleasantville, NY 10570*
22. Fold clothes
23. Have a neighbor or friend with a calm pet visit.
24. Cut pictures out of greeting cards
25. Dress up; fancy or fun
26. Bake homemade bread
27. Sort objects such as beads by shape or color
28. Sing Christmas carols
29. Say "tell me more: when they start talking about a memory
30. Put silverware away
31. Make a valentine collage
32. Play favorite songs and sing together
33. Take a ride
34. Make a cherry pie
35. Read aloud from:  
*Reminisce*  
P.O. Box 5282  
Harlan, IA 51593-0782
36. Dye Easter eggs
37. Match a basket of socks
38. Take a walk
39. Reminisce about the first day of school
40. String Cheerios to hang outside for the birds
41. Make a fresh fruit salad
42. Sweep the patio
43. Color paper shamrocks green
44. Fold towels
45. Have afternoon tea
46. Remember great inventions
47. Play Pictionary
48. Paint a sheet
49. Cut out paper dolls
50. Identify states and capitals
51. Make a family tree poster
52. Color a picture of a flag
53. Cook hot dogs outside
54. Grow magic rocks
55. Water houseplants
56. Reminisce about the first kiss
57. Play horseshoes
58. Dance
59. Sing favorite hymns
60. Make homemade ice cream
61. Force bulbs for winter blooming
62. Make Christmas cards
63. Sort playing cards by color
64. Write a letter to a family member
65. Dress in red on football Saturdays
66. Pop popcorn
67. Name the presidents
68. Give a manicure
69. Make paper butterflies
70. Plant a tree
71. Make a May basket
72. Make homemade applesauce
73. Finish famous sayings
74. Feed the ducks
75. Mold with play dough
76. Look at pictures in a  
*National Geographic*  
National Geographic Society  
PO Box 2895  
Washington, DC 2077-9960
77. Put a simple puzzle together
78. Sand wood
79. Rub on pleasant scented hand lotion
80. Decorate paper placemats
81. Arrange fresh flowers
82. Remember famous people
83. Straighten underwear drawer
84. Finish nursery rhymes
85. Make peanut butter sandwiches
86. Wipe off the patio furniture
87. Cut up used paper for scratch paper
88. Take care of a fish tank
89. Trace and cut out leaves
90. Ask simple trivia questions
91. Finish quotes
92. Paint with string
93. Cut out pictures from magazines
94. Read classic short stories
95. Put coins into a jar
96. Sew sewing cards
97. Put bird feed out for birds
98. Clean out a pumpkin
99. Reminisce about a favorite summer
100. Roll yarn into a ball
101. Bake a birthday cake

# BOOK LIST FOR THE ALZHEIMER CAREGIVER

## ALZHEIMER ASSOCIATION – UTAH CHAPTER

The 36 Hour Day – A Family Guide to Caring for Persons with Alzheimer’s Disease, Related Dementing Illnesses and Memory Loss in Later Life by Nancy L. Mace, MA and Peter V. Rabins, MD, MPH from John Hopkins (Available in English & Spanish)  
*Highly Recommended*

Alzheimer’s Activities: Hundred’s of Activities for Men & Women with Alzheimer’s Disease & Related Disorders by B.J. FitzRay

Alzheimer’s Early Stages by Daniel Kuhn, MSW

Alzheimer’s Sourcebook for Caregivers – Practical Guide for Getting through the Day  
By Freda Gray-Davidson

And Thou Shalt Honor: The Caregivers Companion by Beth McLeod

Best Friends Approach to Alzheimer’s Care by Virginia Bell and David Troxell

Caregiver’s Guide and Source Book (3<sup>rd</sup> Edition) by Howard Gruetzner

Caregiving: The Spiritual Journey of Love, Loss and Renewal by Beth W. McLeod

Complete Guide to Alzheimer Proofing Your Home by Mark L. Warner

Counting on Kindness: The Dilemmas of Dependency by Wendy Lustbader

(The) Forgetting: Alzheimer’s - Portrait of an Epidemic by David Shenk

How to Care for Aging Parents: A Complete Guide by Virginia Morris

Kind Words for Caring People: Daily Affirmations for Caregivers by Sefra Pitzele

Living with Grief: Alzheimer’s Disease by K.J. Doka

*These books are available at most bookstores or  
on-line at Amazon.com*